

First and Last

Closing Learning Disabilities Hospitals



Mark Brend



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"First and Last is a book that tells a story that needs to be told, and it tells it with passion, accuracy and a flair for engaging the reader. As Chief Executive of Turning Point I was scandalised when I was told stories by our clients of not being able to choose what clothes to wear, or whether or not to have sugar in their tea. I was equally disturbed by the descriptions of people with

learning disabilities as difficult or challenging, when, on further investigation, you found that they had been denied basic rights in favour of administrative convenience, in circumstances that would make anybody (certainly me) exhibit 'difficult' behaviour. This experience and these stories led Turning Point to mount a campaign in 2003 to remind the Government of their target to close long stay institutions. To our alarm we found that the target was nowhere near being reached, and that, in fact, many trusts were being left to decide when they would act because of other pressures. We also found some quite cynical practice of redefinition of long stay hospitals as campuses (same thing, different name) in order to avoid appearing on the closure list. Turning Point also came across many moving expressions of fear and concern by families and carers who felt that any change was a bad thing, or who were simply confused and had not received clear communication. Our campaign got the Government to re-commit to change and meeting targets. The most important experience for me in the campaign was a Turning Point service user who we had transferred out of a long stay institution, who had been labelled difficult. At a learning disabilities conference he told his story, and when a minister gave his speech and made the excuse that managers are finding the target challenging, stood up and said loud and clear "that's rubbish, minister; that's rubbish!" At the heart of this story are the lives of people whose voice needs to be heard and whose lives need to be turned around. Well done for telling a story that needs to be told."

Lord Adebowale CBE

Visiting Prof Lincoln University
CEO Turning Point

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Foreword

I regard it as both a pleasure and a privilege to have been invited to produce the foreword for this reflective and insightful book. During the past four decades I have been personally associated with the lives of people with learning disabilities, their carers and their professional supporters. Together, we have witnessed many changes, which overall have resulted in the enhancement of the rights, status and societal position of some of the most marginalised members of our community. However, as this text will bear witness, the journey towards meaningful inclusion within society is far from concluded.

Indeed the need for further investment and strategic commitment to improve the lives of people with learning disabilities was acknowledged only last year by the Secretary of State for Health, who in his foreword to a review of policy stated:

“Six years on I, and many others, believe that what we said should be achieved in Valuing People was right. We have seen some good progress in some areas but unfortunately, for far too many people with learning disabilities, much has remained unchanged. Valuing People: The Story So Far, published in 2005, set out what had been achieved and the areas in which much more progress was required. Two years on from that report, we are still faced with the same challenges, particularly in ensuring that people with learning disabilities can access mainstream services for health, housing, education and employment – the things that ensure equality of citizenship.”ⁱ

This inspiring text takes us back on a journey that reflects accurately the rites of passage that so many people with learning disabilities experienced as they moved from long stay institutions into the community. It provides a rich tapestry against which to judge the key stages of transition that they and the staff who worked with them experienced as the hospitals that they once called home finally closed their doors on a secret world, ignored and forgotten by the majority of the population. Through reliance on narrative witness accounts of

the closure of five hospitals, the author has synthesised the characteristics of the lifestyle shared by many thousands of people with learning disabilities and in so doing provides a sense of corporate memory to inform the next generation of service development.

It is the book's reliance on the inclusion of personal testimony and informed vision that sets it apart from other books. As such it records the origins of the journey from hospital care and quite correctly acknowledges the contribution that voluntary sector organisations such as Choice Support have made to enhancing the lives of people with learning disabilities by enabling them to experience both meaningful and integrated lives within the context of their local neighbourhoods. This organisation has been at the forefront of national service development and at the heart of its philosophy has been the consistent promotion of the 'person' as a user of services, placed centrally at the heart of its activities and governance arrangements. In so doing Choice Support has provided an impressive range of innovative and pragmatic service responses and solutions, designed to promote inclusion.

Part of Choice Support's success must be attributed to the role that it has played in the relocation journey. Indeed it was there at the beginning when the first hospital, Darenth Park, closed and is engaged currently as a key provider for one of the last hospital complexes to close – Orchard Hill in the London Borough of Sutton. It is this cumulative experience, based on the personal testimony that so many service users have presented to Choice Support, which has been pivotal in driving its success. Its services have penetrated the actual lives of service users as co-agents of change by offering real choice and self-determination.

It is my contention that the realisation of excellence in the design and delivery of responsive services relies upon the principle that service

users, their carers and support staff require (and deserve) mutual recognition as key stakeholders in the development and implementation of future policy imperatives. This text aims to ensure that this principle becomes a reality but also confirms that further investment and commitment to improving the quality of life experience for people with learning disabilities is required.



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May 2008

Author's note

In most areas of life terminology tends to change over time, and the learning disability world is no exception. When I started work in learning disability services in 1988 the term 'learning difficulty' was in the ascendancy, though 'mental handicap' was still commonly used (indeed, the organisation I worked for used it in its title). In this book I have chosen, at times, to use terms that have fallen into misuse, some of which now appear offensive. I have done this when I have judged that the historical context demands it.

In some cases names have been changed to ensure anonymity.

The silent minority

In 1982 the Independent Television network screened a documentary by Nigel Evans called *Silent Minority*. Among many disturbing scenes was one showing a young man tied to a post. The narrator reported that the man was restrained in this way for up to five hours a day. Another scene showed other people – bruised, half-dressed, sunburnt as a result of drug-induced skin sensitivity – wandering aimlessly in a fenced compound. Elsewhere, collections of people in large, shabby, sparsely furnished rooms, rocked aimlessly to a background chorus of hums, groans, and an unwatched television.

The documentary was disturbing not just for the terrible scenes it depicted, but because all of them were filmed in National Health Service (NHS) mental handicap hospitals. In a free democratic society, at a time in social history when all manner of minority groups were asserting themselves and demanding recognition, equality and respect, this was the care society offered to some of its most vulnerable people.

The man tied to a post for five hours a day lived at St Lawrence's Hospital, in Caterham, Surrey. On a spring morning about six years after he was filmed I found myself driving a small minibus up the imposing drive of that impressive building. I was there as a newly employed support worker, sent to collect two men we – a small charity in North London - were to resettle into the community. This meant moving them to a beautifully appointed luxury flat near the British Museum, in Bloomsbury, central London. Those two men – one in his late 30s, the other in his early 40s – had spent most of their lives in St Lawrence's.

I found them sitting in the reception area on their own, each clutching a small black bin bag. In those bags were an assortment of old clothes, many made of an odd, quick-drying, shiny man-made fabric. They had no other possessions, no toiletries, no personal mementoes such as photographs, no records or cassettes, in fact they had no personal

possessions at all. I do not recall anyone coming out to wave them off. We ushered them into the minibus and drove them to their new flat, which they had visited a few times before. I did not really recognise the implications of all of this. I, like my colleagues, was motivated by an almost evangelical fervour to bring these men 'home'. Actually, Bloomsbury was only home in the sense that both men had been born in the area. One still had family living nearby, although he rarely saw them. The other had lost all contact with his relatives. The idea that either of them would stroll around the neighbourhood basking in a warm sense of homecoming was false. But what happened on that day was not unusual. The truth is that the mentally handicapped (as people with learning disabilities were then referred to) were virtual non-citizens, marginalised, unnoticed, set adrift without most of the basic elements of what we consider constitute a normal life – employment, a social network, money, a home, possessions. And also without power or influence over their own destinies. Almost uniquely, they were categorised as a sub-group amongst British citizens that had not committed crimes, and kept apart from mainstream life for most of their lives, then moved somewhere else without any say in the matter.

Silent Minority was not the first scandal about mental handicap institutions, and nor would it be the last. Rather, it was one of many events that drove forward a desire to end institutional care for people with learning disabilities. This short book is not intended as a complete history of the closure of mental handicap institutions in England. Rather, it tells the story of one organisation, Choice Support, and its engagement with the community resettlement process, from its beginning to its end.

Special protection

“Putting people with learning disabilities in hospitals and large-scale institutions was a scandal which disfigured our society.”

Ivan Lewis, Social Care Minister; August 2007.ⁱⁱ

People with learning disabilities have always been with us: they are not a new phenomenon. Having said that, they have become more visible in recent decades. There are several reasons for this, not least that improved medical care has meant that many profoundly disabled people, who may also have health problems, now survive into adulthood due to advances in medical care, whereas until quite recently they would have died at birth or in infancy. Another reason is that changes in social and health policy over the past few decades mean that people who would otherwise have spent their whole lives in institutions, isolated from mainstream society, now live on the same streets as you and me, go to the same shops, attend the same places of worship, and use the same leisure centres. For much of the 19th and 20th centuries this was not the case. Before that, the little we know about the lives of people with learning disabilities in England suggests that institutionalisation was not always the norm through history.

One problem in unravelling a history of learning disability is that it is often confused with mental illness. References in medieval laws to people ‘not of whole mind’ might well include people with learning disabilities, but also the mentally ill. This confusion continues even now. Much suspicion about community care policies – a staple theme of the hand-wringing media in the 1980s and 1990s – is based on this misunderstanding, which, at its extreme, can group a person with a mild learning disability with a violent criminal with multiple personality disorders. Sections of the media tend still to describe both as ‘mental patients’ or something similar.

Those same sections of the media will sometimes resort to a sort of demonization of the mental patient who commits a crime, and in

doing so perpetuate unwittingly another archaic perception. In medieval times people we would now consider to be mentally ill – and because of the confusion between categories, the learning disabled too – were sometimes thought to be possessed, or to be witches, or for some other supernatural criteria to be applied to explain their condition. Society's response to this might have been physical and mental torture, and sometimes execution. But not all – or even most – learning disabled people were subject to such barbarities throughout English history.

References to a state or civic responsibility to care for and protect people with learning disabilities start to appear in the 1200sⁱⁱⁱ. There is evidence that some aspects of what we now call learning disability was not only recognised, but that tests of people's capacity to perform various tasks were used as a diagnostic measure for it.^{iv} It is clear, too, that attempts to support and care for 'natural idiots', which were humane in intention at least, ran continuously from these times up until the 20th century.

These two attitudes – fear and hatred on the one hand, a paternalistic desire to care for and protect on the other – found expression in official responses and legislation that strengthened the institutional case in the Victorian and Edwardian eras. In the 1904-08 Royal Commission On Care And Control Of The Feeble-Minded is the statement: "Our first principle is that persons who cannot take a part in the struggle of life owing to mental defect ... should be afforded by the state such special protection as may be suited to their needs." In other words, the emphasis is on care and protection, of which the disabled person becomes the passive recipient. In contrast, The Mental Deficiency Act of 1913 describes the 'feeble minded' person as 'parasitic and predatory', and a 'potential criminal'. He or she is someone to be feared, to be suspicious of, someone who poses a threat that needs to be contained. This tension between care and containment became a defining feature of the mental handicap institution.

Apart from state responsibility, for centuries there would have been some charitable alms administered locally, if irregularly, too. Perhaps the fictional archetype, the village idiot – a character generally tolerated more or less benignly – has its roots in real people with mild learning disabilities, able to live independently to an extent, but getting some state provision or charity.

Private madhouses did exist, and probably contained not only the seriously mentally ill, but the more profoundly disabled who had survived into adulthood. Conditions in madhouses would have been poor. The first of a very long line of reports to parliament exposing the scandal of such institutions was delivered in 1763. It was followed 11 years later by the Act For Regulating Madhouses.

Throughout much of the 19th century provision for people with learning disabilities was bound up with provision for the ‘poor’ in general. One consequence of this was that some found themselves placed in workhouses. But by the middle of the century the notion of the asylum began to take hold. Stripped of the negative connotations the word holds today, the asylum was meant to be a place of safety and refuge, of peace and tranquillity.

Park House, in Highgate, north London, the first ‘charitable asylum for idiots’, opened in 1848. The 1867 Metropolitan Poor Act provided for asylums to replace workhouses for ‘mental defectives’. It was followed by a succession of statutes through the Victorian and Edwardian eras, up to the 1913 Mental Deficiency Act, which created the pattern of learning disabilities provision for much of the 20th century. Although it allowed for alternative models, it favoured colonies, another word to describe long-stay mental handicap hospitals. These places were closed communities, with hierarchical management structures, governing rules, their own places of work, shops, hospitals, cemeteries “...all aspects of life ... conducted in the same place and under the same single authority.”^v

Although a popular perception persists that all mental handicap hospitals were crumbling Victorian buildings, many that became the subject of closure programmes in the 1980s and 1990s were actually set up in the 1920s in response to the 1913 legislation. Furthermore, new hospitals such as Fieldhead, in Wakefield, were being built as late as the 1970s. The Victorian hospitals were generally set up originally either as workhouses, private asylums or general hospitals. Management of the hospitals was split between local authorities and private and charitable bodies, until the creation of the NHS in 1948. At this point most hospitals came under the jurisdiction of the NHS, although some private and charitable concerns remained.

Regardless of when they were actually built and who managed them, these institutions were often located on the outskirts of towns or in the countryside, cut off from the day-to-day lives of most people. And those that were not geographically isolated remained socially and culturally out on a limb – hidden worlds within worlds. Although it must be true that some institutions were better than others, the fact is that they all shared similar features, so that conditions in one were almost bound to be replicated in another: poor staffing levels, run down facilities, low morale and so on.

To subsequent generations of activists and professionals raised on the changing attitudes of the 1960s onwards, the mental handicap institution of old became a place of mythical horror, almost analogous with a system of complete social control and institutionalisation. This view often extended into a distorted perspective of the motives of the staff who worked in the institutions, and those who set them up in the first place. This distortion was one of the characteristics of the early days of the mental handicap hospital closure process, with the people engaged in moving patients into the community assuming moral superiority, and disregarding any knowledge or expertise held by hospital staff.

Though it is true that many institutions did become unacceptable places in which to live, to automatically bracket all hospital staff as either uncaring about the welfare of their patients, or just plain malicious, was unfair; and had many negative repercussions for the first people to move out of hospitals such as Darenth Park, in Kent, one of the very first to close.

“Now that I am older and wiser [I am] left with a deep sense of respect for the staff of Darenth Park who were not well supported by our efforts. If I could undo anything it would be the disrespect we showed good people trying hard to do a good job in an enormously complex environment.”^{vi}



Nan Carle

Program Manager, Home and Community Services, Division of Developmental Disabilities, Tucson, Arizona

Southwark Consortium/Choice Support co-founder

Board member 1984-1991

Board Chair 1988-1991

It is also wrong to think that the hospitals were set up by cold-hearted bureaucrats and doctors to control inconvenient people. Actually the intentions of the pioneers of the asylum movement were generally humane, their motivations not that different from those of people who later strove to dismantle their work. Nonetheless, the social and often physical isolation of the hospitals did allow subcultures to develop where behaviour that would be immediately recognised as abusive, bizarre, cruel, or unfair outside the walls of the institution somehow became acceptable within.

A case in point is Normansfield Hospital, which occupied more than 40 acres just south of London between Hampton Wick and

Teddington. It was opened in 1868 by John Langdon Down, who first identified the condition that took his name, Down's Syndrome. Down was an early pioneer of attempts to care for people with learning disabilities humanely and respectfully. For many years Normansfield was considered a model of good practice, yet eventually it became the subject of an inquiry in 1979, which highlighted poor standards and a declining environment.

This isolation was not just geographic, but extended into the professional world. In the 19th century Down's decision to dedicate his life to the care of 'idiots' was considered bizarre and a waste of talent by many of his contemporaries. Why would a particularly able student such as Down choose to waste his abilities in a medical backwater? This sense that mental handicap in general, and mental handicap hospitals in particular, were the poor relations of the medical profession, isolated and often ignored, continued into the late 20th century. Speaking in the wake of the Orchard Hill hospital scandal, more of which later, David Congdon of MENCAP stated that "where learning disability services are tacked on to organisations that have got much broader responsibilities [i.e. the NHS] no one is very interested in what's going on."^{vii}

Why is this? Because it is an anomaly having health services responsible for people who may be severely disabled, but not all of whom are necessarily ill. Health services, understandably, think in terms of treatment and cure, and measure their effectiveness in successful delivery of these approaches to care. But if disabled people can not be 'cured', then by its own definition any medical model of service delivery is doomed to perpetual failure, resulting in services that do little for the quality of life of the people being cared for, and crush the morale of staff. This depressed and depressing situation led to a lingering belief that because the severely disabled had no quality of life in mental handicap hospitals, they could never have any quality of life at all. Some thought that there was no chance of improvement, making the job a repetitive, soul-destroying maintenance exercise. The connection was

rarely made that the absence of any acceptable quality of life could be linked to the very care environment itself, and that a change in that environment might lead to better lives for both the people with learning disabilities and those staff employed to care for them.

So grim were the majority of hospitals that in 1974 The Guardian reported a story about a psychiatrist speaking at a medical conference, who had advocated taking medical students on a tour of a ward of a long stay mental handicap hospital, the clear implication being that the miserable half lives lived out by patients in such places might serve as a corrective to over zealous doctors seeking to prolong the life of severely disabled babies.^{viii}

There was little glamour in overseeing a run-down institution full of people often forgotten by their families, and always unvalued by society. Choice Support's current Chief Executive, Steven Rose, trained as a mental subnormality nurse in the early 1970s, and recalls how easy it was to get a job, with the interview and selection process being undemanding and easily navigated – an experience common to many.

Staffing levels in mental handicap hospitals were, probably without exception, woefully inadequate. Two nurses to at least 20 patients was normal, and sometimes it was considerably worse than that. Faced with such circumstances, providing any sort of pro-active, stimulating support or even entertaining activities was simply impossible, and care was reduced to a mechanical performance of physical necessities – bathing, feeding and so on:

“People were treated absolutely terribly. One of my memories of how people were dehumanised is of one of the secure wards. In those days patients were issued with a denim suit, they had no clothes or possessions of their own. There were nine inches between the beds in the dormitories. Everybody had a bath on a Saturday morning. Two of us would bath seventy people. There were two baths in one bathroom, with no privacy between them. Seventy men would line up down the corridor,

naked, clutching their clean bundle of clothes and towel. That was presented to me as acceptable, and everybody did it.”^{ix}



Steven Rose

Group Chief Executive, Choice Support

Part-time auxiliary nurse 1974

Student nurse 1975 - 1978

Tatchbury Mount Hospital, Hampshire.

The sense of hospitals being closed communities often extended to the staff. Some lived on site, and it was common to find networks of relatives working in single hospitals. Lisa Gregg-Herrett, who has worked for Choice Support for many years, was a student nurse in a mental handicap institution:

“It was a difficult place to work, in that it was a very closed environment. A lot of staff were related to each other. People lived on the site – there were staff houses and nursing homes. It was a little community, and I think the only way to survive was to become part of that community. You soon learnt that if you said you did not like the staff nurse on a ward, it was going to be somebody’s wife, or somebody’s aunt. It was a very insular place.”^x

Lisa Gregg-Herrett

The experience of most long-term residents of such hospitals must have been appalling, although due to the disabilities of many of the people contained in such a way, complaints were rare. Sadly, as most people had lived most of their lives in such bizarre and self-contained communities, they had few expectations of a better life:

“Many patients hadn’t experienced anything different – they’d been there for a long time, from age three or even younger ... I can not recall anyone every coming to me and saying ‘I wish I did not live here’. I do not think that they knew there was another life.”^{xi}



Lisa Gregg-Herrett

Assistant Director, Quality and Staff
Development, Choice Support

Student nurse 1985 - 1988

Harmston Hall Hospital, Lincolnshire

One common feature of mental handicap hospitals was an unofficial hierarchy amongst the patients themselves, with the more able earning privileges and having more freedom. The terms ‘high grade’ and ‘low grade’ were common currency amongst both staff and patients: high grade referring to the more able, low grade those with multiple support needs. High grades tended to be proud of their enhanced status, and derived much of their sense of self worth from the label. Low grades, on the other hand, were the bottom of the pile, and were often, too, referred to in infantilising terms such as ‘babies’. And it was the high grades that got most attention, while the low grades, the very people in need of most support, actually got less:

“Some of the more able people became a sort of unpaid help – they worked in the garden, the kitchens, the laundry, for money they spent on cigarettes. Patients in that situation were very favoured. They saw it as a positive thing as it meant they were respected by the staff.”^{xii}

Lisa Gregg-Herrett

“I used to work, mopping the floors. We used to get a wage packet once a month. I used to spend it on sweets, and sometimes I bought myself some soap and toothpaste. The nurses used to take us out to the shop, only once a month.”^{xiii}

Brenda Moore

Hospital Patient 1950s – 1980s

Physically restraining challenging patients was normal. Options included detention in isolation rooms, staff holding patients, the use of tranquilising drugs and, in some cases, tying patients to beds, wheelchairs or posts.

“They used to put me in the side room and make me sleep in there, then let me out in the morning. I did not like it in there - it was ever so dark. I went ever so wild.”

Brenda Moore^{xiv}



Changing attitudes

“Our goal is to see mentally handicapped people in the mainstream of life, living in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their community.”

An Ordinary Life – King's Fund 1980^{xv}

The 1960s was an era of cultural and social revolution, and although mental handicap hospitals were outwardly untouched by the upheavals, it was in this decade that voices, initially few and scattered, were raised questioning institutionalisation as a model of care for people with learning disabilities. Eventually those voices became a powerful lobby that influenced government policy.

Although mental handicap hospitals continued to exist through the 1960s and 1970s, and some new hospitals were opened even as plans were made to close others, there was a marked shift in societal attitudes. This shift was driven by two factors.

Firstly, a series of scandals about treatment of patients and general conditions in mental handicap hospitals fed a growing public realisation that they were not quiet peaceful places in the country where distressed people could relax, but controlling, restrictive environments run by under-resourced, over-stretched and sometimes abusive regimes. Between 1969 and 1979 there were eight major inquiries into conditions and practices in mental handicap hospitals in England and Wales. These were prompted by concerns ranging from doubts about general standards and care and working practices, to more specific allegations of staff cruelty to patients, and financial irregularities. Conclusions tended to be similar, the recurring themes being overcrowding, isolated and impoverished environments of care, poor staffing levels, low staff morale, and a lack of meaningful activity for patients. These inquiries were accompanied by flurries of media coverage, and indeed were sometimes prompted by initial reports in

newspapers. The public inquiries commenced with the 1969 report about Ely Hospital, Cardiff, which was commissioned by the Labour government of the day in response to allegations raised first in *The News Of The World*.^{xvi} The inquiries concluded in 1979 with the publication of the infamous *Inquiry Into Care At Normansfield*, in Teddington, south west London.

Secondly, philosophical debate was posing questions about the model of care. If mentally handicapped people are not ill, then why are they being treated in hospitals? Surely most mentally handicapped people could live more independently if they were only given more opportunities and support? Shouldn't mentally handicapped people have rights like the rest of us? There was a gradual, but eventually unmistakable, shift in attitudes towards people with learning disabilities, away from the notion of directed care, towards the notion of providing and facilitating support for self-determination and independence.

These new ideas began to find expression in influential policy directives and publications. In 1971, for example, the United Nations published its *Declaration Of The Rights Of Mentally Retarded Persons*, and in 1972 Wolfensberger published *The Principle Of Normalisation In Human Services*, which would become a seminal text. Nearly a decade later many of the new ideas coalesced in a King's Fund publication called *An Ordinary Life*, first published in 1980, and reprinted in 1982 and 1984. Its ideas became a manifesto for the generation of activists, professionals and parents who shaped learning disabilities services in the 1980s. It was a group of people driven by these ideas that first formed Southwark Consortium, which would become Choice Support.

Alongside these philosophical shifts, formal official policy – the world of White Papers, statutes, inquiries and committees – was moving away from institutional care too. The idea of community care was first mooted back in the 1950s, though a White Paper *Better Services For The*

Mentally Handicapped (1971) noted that little had been done about it. That same document plotted a course away from large-scale institutional care toward community care over the following two decades. It stated the principle that people with learning disabilities should not be 'unnecessarily' segregated, and hospital places should be reduced by half by 1991, with a corresponding increase in community placements. Even then change was a long time coming, and an Audit Commission report into the progress of hospital closure in 1986 noted only a 39% progress toward the planned reduction in hospital provision.

It is against this background of emerging ideas and legislative change that events in Southwark in south east London in 1984 must be viewed. In the borough at the time there was a pressing problem that needed a solution. A large mental handicap hospital near Dartford, Kent, called Darenth Park, was set to close. The decision to shut it had been made as far back as 1973, but inertia and a lack of clarity about what to replace it with had resulted in slow progress. It was to Darenth Park that many Southwark-born mentally handicapped people went to live at some point in their lives, often when ageing and infirm parents could no longer care for them. The planned closure of the hospital had two implications. Firstly, a group of people already living there, many of whom had been residents for decades, would have to move somewhere else. Secondly, mentally handicapped children and young adults currently still living at home in Southwark who might, in the old way of things, have expected to move to Darenth Park at some point, would now have to be cared for in another way.

Several developments to tackle these problems, which were in essence smaller residential institutions, were already being planned when a group of like-minded people applied themselves to putting the principles of *An Ordinary Life* into practice. Representatives of Lewisham and North Southwark Health Authority (one of two Health Authorities in Southwark, along with Camberwell Health Authority) and a local housing association approached Cambridge House with a proposal in 1983. The idea was that Cambridge House,

a community voluntary organisation in Southwark, would host and manage a new housing and support scheme for mentally handicapped people. The involvement of Cambridge House was crucial as the scheme needed to be managed by a voluntary organisation to qualify for capital and revenue grant aid from the Housing Corporation. This initiative led to a conference on 28th January 1984 at the North Peckham Civic Centre, attended by 120 interested people. It was at this conference that the group that had been planning for six months sought, and obtained, endorsement for their ideas. Southwark Mental Handicap Consortium, as it was first called, was born.

Initially Southwark Consortium was primarily a housing management agency, working with various housing associations and statutory agencies. All of these organisations were represented on Southwark Consortium's board, making it a true partnership. It was the first consortium of its type in the UK, and by 1992 there were more than 40 similar organisations across the country.

The First – Darenth Park

“Can you remember the day you left Darenth Park? What was it like?”

“Well, strange. Strange it was ... it would be wouldn’t it. Got to get used to it, ain’t I? Well, I was there all my life. I was there in hospital for most of my life ... when they brought all of my property up [to the new Southwark Consortium house] it was all over the show. Took me nearly a week to straighten it out. No-one helped me.”

Extracts from recorded conversation held in 1999 between Julia Honess and the late Bill Surrey.^{xvii}

Darenth Park Hospital could trace its history back to 1878, when Darenth School was built in countryside near Dartford in Kent. It was founded to cater for 500 mentally defective children. Within a decade it was home to 1,000 children and adults. In 1911, almost a self-sufficient community due to the constant stream of free labour, it was renamed the Darenth Industrial Trading Colony. In 1936 it became Darenth Park Hospital.

The hospital was assimilated into the newly-formed NHS in 1948, serving a catchment area covering south east London and Kent. By 1970 the population had grown to 1,500, crowded into run-down and poorly-equipped wards. In theory at least it was animated as an institution by notions of care and protection. Attempts were made to enrich the lives of patients, but these were built on a foundational belief that people with learning disabilities could not function in open society.

In 1972 The Guardian ran a short feature titled ‘Jobs for the subnormal’, which reported on an initiative that saw Darenth Park patients bussed off to an industrial estate in Dartford to work in a packing factory. Although aspects of the story would resonate with contemporary audiences – the importance of work to a sense of self-worth, the non-disabled staff accepting their disabled colleagues – the attitudes of the hospital, and indeed the times, are revealed as the

article progresses. The pay for the work went straight to Darenth Park, not the men themselves, while Dr Rosenberg (a consultant psychiatrist at the hospital) said this:

“The chaps ... are severely subnormal and can never really hope for anything like a normal life. That is why it is so important to them to have the responsibility of going out to work...”^{xviii}

In 1973 the Regional Health Board decided to close Darenth Park, but it would be more than a decade until Southwark Consortium formed to facilitate people leaving. Initially, Southwark Consortium planned to develop more than 100 places in normal housing over two to three years, a figure that would double by the end of six years. That proved to be unrealistic, but nonetheless people started to move out of Darenth Park into houses in Southwark in large numbers from 1986, and by 1988 Southwark Consortium was managing accommodation for more than 90 people.

With hindsight, there was much about this transition that was ill planned and poorly executed. Stories of a double decker bus filled with hospital patients and their paltry belongings turning up at a newly-built campus in Crystal Palace, to be almost randomly allocated places in the various bungalows that they had never seen before, are, sadly, not entirely apocryphal.

Nonetheless, a sense of moral urgency derived from the ideals and values of its founders drove and energised Southwark Consortium's work.

“We were seeking to reform the whole of the way people with learning disabilities experienced the service system. We did not understand ‘no’ nor ‘we can not do that here’, nor did we accept the mediocrity of ‘the greatest good for the greatest number’. We were passionate in our belief that we could create a world where there was not an ‘us and them’.”^{xix}

Nan Carle

There was a real sense that people living at Darenth Park had to get 'back home' as soon as possible. This was well-intentioned, and there is no doubt that many of the people who did move during this phase settled into lives much richer and more varied than they had previously experienced in hospital. However, the organisation's urgency meant that some people, and their families and future neighbours, were unsettled.

One particularly sad phenomenon was that relationships between people who had maybe shared a ward in hospital were not always valued or even noticed. This sometimes led to friendships decades long being ruptured, by the simple expedient of moving people a few miles from each other. These people, unable to navigate their way across what would have appeared to them a vast swathe of intimidating unfamiliar territory, and lacking the confidence or verbal dexterity to ask for help, lost each other. The development of a closer working relationships between hospital staff and Southwark Consortium managers might have prevented this from happening on occasions, but the relationship between the two camps was characterised by suspicion, and sometimes overt hostility.

Actually, many former Darenth Park staff did come to work for Southwark Consortium in the end, but any knowledge they may have had about people's earlier lives in hospital was not systematically collected and integrated in the new service. In many cases the cumulative rich history of the people who transferred to the new service was lost, or simply forgotten.

It wasn't just hospital staff who were suspicious of Southwark Consortium. Parents, too, were often very anxious about their children leaving hospital, which found expression in criticism of the new organisation. Although few of these parents were actually satisfied with Darenth Park, at its best it did offer a sense of community and shared experience for both patients and their families. Parents worried about how their children would cope living more independently, and given

that it had not been done before, Southwark Consortium was ill-equipped to offer reassurance based on experience.

One of the pivotal beliefs of those times was the notion of returning people to their original communities, to their homes. With hindsight this was also one of the profound weaknesses of the process, as in most cases people had left their home communities many years before, and often had no surviving links with them. Additionally, during the time in which people were in hospitals those communities had changed almost beyond recognition. But the problem was deeper than that. Actually, in a large, diverse central London borough – with very poor and very affluent areas – the very notion of community was dissipated and fractured. There was not – and is not – a single homogenous community in Southwark, as there is not in most parts of most urban conurbations. Rather, Southwark was made up of many micro-communities and sub-cultures, centred around schools, places of work, places of worship, different ethnic groups, pubs, leisure facilities and so on. What was not thought through was that most of these communities were not easily accessible to people with learning disabilities who had spent decades in a hospital cut off from mainstream society. Some, like schools, never would be accessible. So many people became as isolated in the 'community' as they were in hospital, and in many cases it took years before people found their own niche, and made relationships.

The tensions between, on the one hand, support staff motivated by genuinely-held but often naively and insensitively-expressed beliefs, and on the other, hospital staff and some families, were acute and damaging. These tensions, which were mainly about a clash of cultures, often became personal. Working in another organisation on another hospital closure programme a few years later I experienced something of this. I was told by my line manager to 'humour' the hospital social worker who was our main point of contact, the manager clearly thinking of him as a hinderance in the process we were meant to be working on in partnership.

Such attitudes characterised much of the Darenth Park closure, and lingered for many years afterwards, in the form of a polarised 'them and us' mentality. Steven Rose remembers an incident shortly after he took up his post in 1991. In conversation with an occupational therapist (OT) he let it be known that he was a nurse and had trained in mental handicap hospitals. The OT responded by making the sign of the cross, as if warding off evil powers, perhaps not entirely in jest.

The truth is that most people who worked at mental handicap hospitals were trying their best to do a good job, or had at least started out with good intentions. It was the environment and the system that made it impossible to provide patients with a decent quality of life. That the same problems show up time and again through decades of scandals and reports into hospital conditions is not because all those hospitals were full of a particular breed of malicious people, but because the system did not work, and let them down, just as it failed the many people with learning disabilities who lived in them. There was little freedom of choice or privacy, and people were governed by rules that now seem draconian. For example, at Darenth Park visitors were only allowed between 2pm and 4.30pm on Sunday, Mondays and Bank Holidays (but not Christmas Day or Good Friday). Another hospital rule stated that "patients must be prepared at all times to receive any treatment, care, supervision, control and training which the medical council may prescribe." It is no wonder that many people felt an urgent desire then to close Darenth Park and other hospitals like it as soon as possible.

People started to move back to Southwark in 1986, and in August 1988 the hospital shut its doors for the last time, the first large old-style mental handicap institution to close. It was demolished shortly afterwards.

The Darenth Park closure programme might not have been a model of a participative, well-organised hospital closure. Not surprising, perhaps, as the people managing the process had virtually nothing or

nobody to refer to for advice, for models of how it should be done, for standards of good practice, for the simple reason that closing a mental handicap hospital was a new thing. But painful and difficult though the experience was, it did enable Southwark Consortium to learn lessons. These were invaluable, as hospital closure would become a recurring motif in the organisation's life.

The Darenth Park closure programme was well-intentioned but poorly planned. After the initial euphoria of taking people 'back home' evaporated, the reality of supporting a small group of people with diverse needs and different personalities in a community that viewed their arrival with a range of responses from suspicion to outright hostility began to sink in.

In 1989 I was employed by Camberwell Health Authority to manage a Southwark Consortium service. On my first day my line manager greeted me, hands on hips, with the ominous words: "well, you've got your work cut out." She then accompanied me to the service I was to manage, located in a typical Victorian terraced house in a residential street. In it lived just two people, a man and a woman, the man in his mid-twenties, the woman a few years older. The woman, Claire, was a former resident of Darenth Park. The man, David, came from Goldie Leigh Hospital in Surrey. Goldie Leigh was built as an orphanage, then converted into a hospital for children with skin conditions. In 1961, with fewer children needing hospital treatment for skin conditions, a part of the hospital was converted to accommodate up to 52 mentally subnormal children. David had lived there since he was a child, and remained there as a young adult. The hospital was closed in 1988.

The house was in a very poor decorative state, particularly the lounge, which had some large holes in the plasterwork on the walls. The wooden frame of a very smelly sofa was breaking through the upholstery in places. The holes in the wall were, I was told, made by a previous resident who had been 'challenging'. He had recently been moved to an 'out of district placement', a euphemism for a secure institutional facility.

Another woman had also recently been moved on, partly because she did not get on with Claire. The staff team was depleted and demoralised, and within a few weeks of my arrival a further three members resigned, while another was on long-term sick leave.

I was told that my first job was to go and build bridges with the neighbours on one side, who had been making complaints. They were a young couple, both solicitors, and as far as I could judge were generally sympathetic to the *idea* of supporting people with learning disabilities in the community. But they were angry, fed up with being kept up half the night by screaming and banging, and routinely finding their garden littered with objects thrown in by one of our residents. I had no idea what to say to them. My philosophy told me that people with learning disabilities had the right to live in the community, and I fear that I might well have expressed this in a rather insensitive way. I am certain that some of my predecessors did. Looking back, I realise that I would not – then or now – tolerate putting up with the disruption those people experienced. The neighbours on the other side I never saw in the 18 months I managed the service. This was community life.

Although I was soon to find out that I had inherited what had become a notorious problem service, most of the issues it faced were not so unusual in themselves, just slightly more concentrated. Demoralised staff, angry neighbours, service users at odds with each other: these were all common scenarios. But the 'problem' label was relatively new. The service had opened with great optimism, and had for a good while been carried along by a team buoyed up by a shared idealistic commitment to ending institutional care. But that team had broken up, and the service had all but collapsed. Its experiences were typical of the time.

Sonja Jones was a support worker in that first team, employed four months before the service opened to meet future residents and prepare them for the move, and get the house ready. She and the rest of the team received very intensive values-based training for two days

of each working week, and spent the other three visiting Darenth Park. The training emphasised the importance of respecting people, and seeing their behaviour – whatever it was – as communication. This training had a profound effect on Sonja and her colleagues, and she says that even now, 20 years later, it has stayed with her. The team also saw first hand the terrible conditions at Darenth Park. Fired by these experiences, the team sustained the service for about 18 months, dealing with very difficult circumstances that were the result of poor planning that had little to do with them.

The mix of people living in the house was wrong. Three of the four service users were capable of making a lot of noise, and did, so conflict with neighbours separated by just a single thin wall was inevitable. The same three people were physically strong and active, whereas the fourth sometimes used a wheelchair, and was blind. The two women in the house, Claire and Sally, had lived in the same ward at Darenth Park, and had been known *not* to get on. One of the men in the house, James, was considered to be so challenging that at Darenth Park restraint guidelines advised that he should be controlled by six men simultaneously.

Yet despite the combustible mix, the service achieved much. David had been blind since a botched cataract operation when he was a teenager. Before that he had been an active, talkative child, but he became withdrawn and stopped speaking after the operation. In the community service, after a great deal of one-to-one support, he began to talk again. Indeed, by the time I took over managing the service he was talking quite freely. Claire had lived on a locked ward at Darenth Park, where she often attacked staff and other patients, and was controlled with rewards of packets of crisps if she was a 'good girl'. Sonja recalls Claire sitting in that ward rocking, her head covered with bald patches where she had pulled out her own hair. After a few months in the community she was able to attend, and enjoy, a pop concert, looking and acting much like all of the other people present.

But in spite of all of this progress, the service faltered badly, and nearly failed altogether. What went wrong? The answers provide a microcosm of the experiences of community services at the time. Firstly, the service depended too much on committed staff driven by idealism to work beyond what would now be considered the call of duty. When that idealism waned, or people got tired, or simply left to get other jobs, there was no system in place to sustain the service. New staff did not share the bonding experience of values training and visiting terrible hospitals, and the team faltered, unable to renew itself. And the training itself, although it successfully imbued people with a strong sense of mission, did not always provide people with practical tools to cope with difficult situations. What did you do if you were in a pub with a service user and they turned over a table (which is what happened when I first took David to his local)? At what point was it safe to let people who may have never walked down a street on their own go to the shops unaccompanied? What did you do if somebody you were supporting was making a lot of noise at 3am, and the neighbours were banging on your door demanding quiet? Nobody really knew the answers to these questions, because they only arose when people moved into the community. These reasons aside, there was also the particularly poorly thought out mix of service users living in the house to contend with.

Within a few months of my arrival two new residents filled the vacancies. The first was a middle-aged woman who had also been a long-term resident of Darenth Park, the second a young man so able that he was routinely mistaken for a support worker. Our staff team was reconstituted with inexperienced support workers, and we did our best to support the people in our care. I am certain that they ended up doing a lot more things than they had done in hospital. We experimented, not always successfully, with pub visits, meals out, going to the cinema, part time jobs, holidays, art classes and church. But any good we achieved was, I fear, undermined by loneliness and boredom. I do not recall any of the four people having friends, and despite our efforts there was a great deal of sitting around in the house doing very little.

Looking back it is clear to me that we, and indeed people much more senior than us who guided the services, had little idea how to make it all work properly. After I had been at the service for a year we were selected for two weeks intensive in-house training by a team of experts. They spent much of their time teaching us how to support David, the young blind man, to learn to feed himself. At the end of the two weeks he still could not feed himself, but more to the point, he was still friendless, bored and inactive. No-one seemed to know how to address the basic problems of social isolation, a dearth of meaningful and appropriate activities, and the perennial problem of staff disillusionment.

Grove Park and a period of consolidation

“We were absolutely aware that we were not going to make the same mistakes [as the Darenth Park resettlement].”^{xx}

Charan Singh

Southwark Consortium's second hospital closure project was conducted against a different background to the first. Much diminished was the sense of crusading zeal, as the organisation struggled with the reality of managing effective community services. Also, the errors of that first resettlement programme, that loomed large in the collective memory, influenced things, and for the better.

Although Grove Park Mental Handicap Hospital appeared to be a classic Victorian institution, its history was very different from Darenth Park and many other similar hospitals. It was built as a workhouse on a ten-acre site in Lewisham, south east London, in late-Victorian times. The foundation stone was laid in June 1899, and the building work completed in April 1902. In addition to several large three-storey residential wings, facilities included a 400-seat chapel, workshops, a mortuary and a water tower.

During the first World War the workhouse was used as a barracks, then, from 1926 until 1977, as a TB and chest hospital. As late as 1977 it began to accommodate mentally handicapped people, four years after plans had first been announced to close Darenth Park. In this capacity it served for a relatively short time, closing just 16 years later. The site has since been redeveloped for residential use, but some hospital buildings survive.

The closure of Grove Park hospital was a markedly more efficiently managed process compared to the Darenth Park resettlement. This can be attributed to several things, one being that it had a far smaller group of patients (fewer than 90), and better staffing levels. This in turn meant that the quality of service was better than many other hospitals to start with.

Charan Singh (now a Regional Director at Choice Support) worked in Grove Park from 1985 until it closed in 1993, first as a ward manager, then as a support manager. He was part of a resettlement team that managed the closure. This team was a multi-disciplinary body made up of senior hospital staff and others. It was a well-motivated group with shared values, believing that the imminent closure would lead to a better quality of life for residents. It provided strong leadership throughout the process.

Initially staff in the hospital resisted the closure, as did the families of many residents. But the resettlement team worked to persuade people of the benefits, particularly through a three-day training event to which every single member of the hospital staff was invited, including nurses, cooks, cleaners and caretakers. This session concentrated on explaining the values underpinning the resettlement, and why people would have better lives in the community. This was followed by a second phase of training that prepared staff to work in the community.

“We made sure the hospital staff realised that we valued their knowledge, skills and commitment.”^{xxi}



Charan Singh

Regional Director (London and South),
Choice Support

Ward manager and support manager
1985 - 1993

Grove Park Hospital

The staff group were persuaded that the closure would be a good thing, and when the hospital closed in 1993 only two people were made redundant. The remainder moved into community jobs in the services accepting the 20 or so people moving out of hospital care. Many of these staff continue to work as support workers or managers. This successful transfer of staff meant that the Grove Park closure avoided altogether one of the damaging features of the Darenth Park closure, the animosity between new support staff and old hospital staff.

After Grove Park it would be the several years before Southwark Consortium was involved in another hospital closure, a period in which it saw many changes, becoming more recognisably the organisation we see today.

In 1987 Southwark Consortium had been established as an independent charity, having until this point acted under the aegis of Cambridge House. It continued to be housed at the Cambridge House offices for several more years. By 1990 it was managing agent for 44 properties. For the most part, employees of Camberwell Health Authority and Lewisham and North Southwark Health Authority provided the direct support in these houses. It was still very much partnership working, with the Board comprised of representatives of the same group of organisations that contributed to Southwark Consortium's founding in 1984.

The idealistic enthusiasm that had propelled the organisation through its first years was tempered now with a growing awareness of the practical problems of running quality community services. In this respect it was not unique. Many people working in learning disability services throughout the country were questioning the validity of their work, too. The experience of the previous few years had proved that just living in a small ordinary house in the community, as opposed to an institution, wasn't enough *in itself* to radically alter service users' lives. It was a huge step in the right direction, but all too often many

of the features of institutional practice took root in small community services, too. Particularly, it was easy to imperceptibly drift back to treating people as homogenous groups according to their perceived disability, rather than as individuals. So the question became how to design services that were truly for individuals. Grappling with this question stimulated thoughts about how people with learning disabilities themselves could and should have control over their lives and the services they received.

Southwark Consortium funded several special projects in response to this, some more effective than others. A service brokerage scheme ran from 1994 to 1998, which was designed to give advice, information and support to people with learning disabilities to increase their choice and control about the services they received. This can be seen as a harbinger of current working methods, which we will come to later.

Southwark Consortium was formed as a local organisation, to meet a local need. Up until 1997 it continued to work exclusively in Southwark, while many other similar organisations took advantage of the contract culture and expanded beyond their original geographic base. At that point it finally began to look beyond the boundaries of the borough, recognising that a broader base would ensure greater long-term stability. Very quickly the organisation was invited to open new services in the London Boroughs of Hackney (1997) and Greenwich (1998). To mark this move beyond Southwark, the organisation changed its name to Choice Support in 1998. Also, in 1999 the organisation was asked to work outside of London for the first time, helping resettle people from Manor House Hospital in Buckinghamshire. This was the first of three successive hospital closure programmes around the country.

Emerging models of service

“Look for assets and we will find them.”

Nan Carle

In the early years of the new millennium the policy backdrop to Choice Support's work was redrawn. In April 2001 *Valuing People* was published, the first major government plan for 30 years to focus on people with a learning disability. *Valuing People* is based on the values of rights, independence, choice and inclusion, and uses these as a basis for improving services for people with learning disabilities. It came as a validation of Choice Support's work, as the organisation, along with many other like-minded learning disabilities agencies, saw it as a formal policy expression of the values that had underpinned its work for so long.

The sorts of services Choice Support now manages look very different to those it started out with in the mid 1980s. In those days the dominant model of service was the small – or not so small – registered care home. Although some of these survive, most of Choice Support's work is now carried out in supported living services. Supported living is very much a work in progress, and the quality of services being delivered through this model is being refined all the time. At the centre of the model is the notion that people with learning disabilities should be able to live in their own homes, as tenants or owners, with the support they receive tailored to their own circumstances and needs. Typically somebody receiving a supported living service will live in their own house or flat, maybe sharing with one or two other people they have chosen to live with. They will exercise choice over aspects of their life that, in other circumstances, may be beyond their control. These can range from apparently mundane matters like choosing what to eat, and when, to choosing staff to support them. The service is built with the person receiving it in mind. By comparison, most small registered homes have as their starting point some pre-defined notion of what they can do,

into which service users are fitted, whether the fit is comfortable or not. Typically, they house four or more people, and have a permanent staff presence, including an office.

Supported living can be seen as another stage in the journey away from institutional care. The move from hospitals to small registered homes was a move from large scale, segregated, medically-based group care, to smaller, community-based services in apparently ordinary houses. But as we have seen, often the life led in those ordinary houses was socially and emotionally limited, and restricted by lingering institutional practices. Supported living is another step towards not only ordinary houses in ordinary streets, but a standard of life that matches what most of us expect, with a measure of control and choice over what we do, and who we live with.

Services that contained many of the features of what would now be called supported living could be found scattered across the country from the mid-1980s onwards, including some set up by Choice Support in London. But it wasn't until the early years of the current millennium that supported living became a truly mainstream, and widely adopted service model.

For most of us, making plans to give our lives direction is something we do as a matter of routine. None of us has complete control over everything we do or what happens to us, yet we do want to exercise the control we have. We choose to apply or not to apply for jobs, we decide where to go on holiday, we investigate new hobbies and interests, we budget our money so that we can buy what we want and need. Yet for people with learning disabilities in long stay hospitals, this part of human life was missing. They could not make plans about their lives, because they had no control over them. As a response to this, the concept of planning has become well-established in learning disabilities services, but it has evolved in recent years.

The hospital case conference of old was an intimidating affair for the subject, involving professionals sitting in a circle talking about what was best for him or her. Often the person being discussed would not contribute, their presence a mere token gesture. If they were present at all, that is, as such planning meetings often happened without the subject. I recall attending such a meeting in the late 1980s for a woman, Joan, who was moving out of hospital. There were about half a dozen of us present, including the woman whose case we were considering. She sat in silence for the whole meeting, which was mercifully brief. I was keen to ascertain what Joan was interested in so we could try to plan some activities for her when she moved. I asked the meeting what things Joan liked to do, and was told that she did nothing at all. The conversation did not progress, and we were left with the unsatisfactory option of trying things out, a process of trial and error with the emphasis on error.

In early community services more effort was made to involve service users in plans, but there remained for many years a sense that the plans were being made on behalf of the person, by the service. In recent years the focus has shifted, with the rise of person centred planning (PCP). This term is really a piece of jargon to describe something quite simple, which is a person working out what they want to do and how they want to spend their time. But the term is important because it stands in opposition to the previously prevailing way of doing things, which is in effect 'service centred planning'.

Service centred planning is dominated by the service and the professionals it employs, and tends to emphasise someone's perceived problems and needs, and what the service can do to fix the problems. A feature of virtually every plan of this sort generated on behalf of people moving out of hospitals was to develop 'life skills' – cooking, housework, shopping etc. Of course there is nothing wrong with this in itself, but such plans often neglected other basic things crucial to anybody's sense of purpose and well being, notably meaningful relationships, enjoyable leisure activities and work.

In contrast, PCP emphasises the voice of the person and those close to them. It attempts always to establish what the person wants to do, what they like, what they are interested in, and to plan from that starting point. It needn't follow a strict pattern of, say, bi-annual meetings, as other planning systems tend to, but instead the whole process should be constructed to fit the person in question. This sounds quite simple, but it can be difficult to implement. It involves services getting used to the idea of disempowering themselves, and sometimes abandoning their own assumptions. Perhaps the person is not that bothered about learning to cook, but is very keen to get involved in sport. Perhaps they value religious attendance much more than things that the service tends to perceive as marks of independence. It becomes a particular challenge for services to facilitate person centred planning if the person is unable to communicate verbally. How do you find out what such a person wants to do with their life? How do you ensure that you are not just imposing your own prejudices on them because it is easy to do so, because they may not be able to disagree with you? These are real challenges, not easily worked through, and Choice Support would not claim to have all of the answers. Nonetheless, the move towards person centred ways of working marks a tangible shift in values and practices.^{xxii}

In 2007 Choice Support produced a DVD about person centred planning called *Everybody Has Dreams*. It features several service users talking about their plans, most of which challenge traditional assumptions about what people with learning disabilities want, or are capable of doing. One woman, filmed at work, says she needs the job because she is saving to go on a holiday to America, where she will swim with dolphins. A young man talks of his plans to become a sport instructor:

Another strand in emerging thinking about learning disabilities services, and one that is integrated into PCP, is drawn from the Assets Based Community Development (ABCD) approach, a conceptual framework developed by John McKnight, of the Northwestern University's Institute for Policy Research in Chicago, Illinois.^{xxiii} Nan

Carle, Choice Support's co-founder and first Chair (when the organisation was called Southwark Consortium) has helped embed this idea within the organisation through seminars and workshops in recent years.

The approach assumes that all communities have assets, which could include skills, buildings, financial resources and associations of people. By investigating and mapping out these assets they become the focus for planning. This is in contrast to more traditional ways of planning, that focus on problems and unmet needs. The idea is that by concentrating on assets rather than needs and problems, people are more likely to create positive outcomes: "Look for assets and we will find them. Look for problems and that is what we get more of." ^{xxiv}

For a person with learning disabilities planning their life, this approach enables them to look positively and proactively at all that their community has to offer them, and all that they can contribute as well. So, if somebody is moving into a flat on their own from a long stay hospital, and they have no friends, following the ABCD approach could ascertain what the person enjoys – for example, music. It would then map out what music-related social activities are available locally – classes, pubs with live music, church choirs and so on – thus generating options for the person to join in with, and contribute to, which would also, hopefully, lead to friendships forming.

Those changes aside, in some ways the learning disability scene now resembles that of the early to mid 1980s. Then new service models were being developed, driven by people with strong, shared values. There was a sense of mission. In the ensuing years – from the late 1980s through most of the 1990s – the mood was more of struggling to make good ideas work, and a realisation that idealism alone wasn't sufficient. Now, those struggles have been translated into effective ways of doing things that free people once again to nurture and explore their values.

Manor House, Fieldhead and Highbury

“The last person to leave the ward switched the lights off and closed the door.”

Lisa Gregg-Herrett

As its name suggests, **Manor House Hospital, Buckinghamshire**, was built on the site of a manor house. The original building was knocked down in the 1960s and replaced with a campus style development of small residential units, each housing up to 15 people. As such it was considered – in its time – a more enlightened, modern version of the institutional model. The site remains a NHS facility, housing administrative operations and a community learning disabilities team, which means that former residents sometimes return to their old home.

The re-provision from Manor House, which started in 1999, was drawn out. It was not a straightforward process, partly because it was the first time that Choice Support had worked outside of London.

The first hurdle to surmount was finding a housing provider, as although Choice Support had been awarded a contract to provide support and care, there was no housing provision or capital allocation to purchase housing. This led to a relationship with Progress Care Housing Association, which continues productively.

After a promising start, both Progress Care and Choice Support ran into difficulties. A problem arose when the local registration and inspection department of Buckinghamshire County Council demanded that all the schemes be registered as care homes, an impractical proposition as several properties had already been purchased and could not be physically adapted to meet registered care standards. It took almost a year to obtain an agreement that the services should instead run as supported living schemes, as they were intended.

Then it proved difficult to establish the housing benefit levels required

to fund adaptations to homes in an area where property prices were very high. These two delays meant that the re-provision programme took much longer than initially proposed, and as a result the reputations of both Choice Support and Progress Care became tarnished in the eyes of commissioners.

More positively, this was also the first hospital closure programme where person centred planning approaches were used, with each individual service user having an essential life style plan. Eventually 30 people moved into Choice Support services from 2000, with the final house opening in 2003. Today the standard of housing in Buckinghamshire remains among the highest in Choice Support, and the services enjoy very good Commission For Social Care Inspection (CSCI) and Supporting People ratings. There is a consensus, too, amongst commissioners, regulators and parents that service users' lives have been enriched enormously.

Just as the Manor House resettlement was coming to an end, Choice Support embarked on a bigger project moving people out of **Fieldhead Hospital in Wakefield, Yorkshire**. This would take three years, from 2002 to 2005.

Fieldhead Hospital was built in the early 1970s to accommodate people moving from older institutions such as Oulton Hall and Hatfield Hall, which had closed. Opened just as plans were taking root to move away from hospital-based services, Fieldhead was intended as a short term measure, with the proviso that people would be resettled into the community within 15 years. This did not happen.

It was a campus development, the wards housed in single-storey buildings, called villas, each accommodating about 30 residents and staffed at any one time by two or three people. The campus model was generally considered to be a more humane and progressive service model than the older hospitals, but actually apart from

architectural differences, little changed. Life inside was much the same. Residents lived four or five to a bedroom, and ate in a shared dining room food that had been prepared in a communal kitchen.

Other facilities on site included a school (as there were children's wards as well as adult's), and a training centre with a woodwork section. There was a purpose-built 'locked' ward, and most villas were built with some locked rooms to isolate challenging patients, which were later changed into rooms for general use. A social hall held parties and church services, and every Christmas staff and residents joined together for a Christmas social at a local ballroom. There were communal holidays and occasional day trips.

Kathryn McLoughin lived in Fieldhead for several years, the last stop in a long hospital career that started when she was 11 years old. She now lives in a small flat shared with one other person, and is supported by Choice Support. Her recollections of life in hospital indicate that there was a sense of community and friendship that has not – yet – been replicated in community life. This loss is balanced against a much more personal and responsive level of support and more choice and control over her life. Now she gets one-to-one support, then there were two or three staff to every thirty people. Now she can choose what to eat, when and where, then she ate what she was given, at appointed times. And wore a green apron for every meal, even when on holiday.



Kathryn McLoughin

Hospital patient

Children under 16 living at Fieldhead were resettled in the 1980s, but several attempts to shut the hospital in the 1990s failed. Fieldhead eventually closed its learning disability services in 2005, by which time 37 people had moved onto Choice Support services. It remains open as a community mental health resource.

Karen Singleton, a director at Choice Support, managed the organisation's work supporting people to move out of Fieldhead. Choice Support was one of three providers involved initially. The people moving out of hospital were all aged somewhere between about 45 and 80, and had spent decades in various institutions. Many had initial anxieties about the prospect of moving out, and because they had so little experience of making decisions about their lives, most found it difficult at first to express views about what they wanted their new homes to be like. This meant that Choice Support had to work closely with service users, their families, care managers and English Churches Housing Association, which provided the housing, to gradually develop profiles of what new services should look like, and what needs they would have to meet. From this process, many new homes were specially commissioned and built, and some existing properties purchased and modified. Choice Support also took on the management of a number of group homes previously managed by the NHS, and owned by Chevin Housing Association, in which a number of former patients of Fieldhead had been living for some years.



Karen Singleton

Regional Director (North),
Choice Support

It is a feature of all mental handicap hospital closures that some hospital staff resist change. Relatives of services users are often concerned, too. Fieldhead was no different, but Choice Support was able to draw on recent experience by inviting some staff and relatives from its newly-opened services in Buckinghamshire to talk about their experience of the closure of Grove Park. They too had been anxious or even directly opposed to Choice Support's objectives, but had come to see that the lives of the people they supported had improved immeasurably since they had moved into community services. That visit influenced the perceptions of people involved with Fieldhead, both staff and families. Another powerful tool in winning people over was the tangible and obvious quality of the new and refurbished properties being developed to house former patients.

In the end most staff came to feel positive about Choice Support and its plans, and Karen Singleton praises them for "[changing] their own practices and giving so much to the lives of the people they support."^{xv} Most, but not all. One manager insisted on taking a drip stand from the hospital into the new community service she was managing, a symbol, perhaps, of an unwillingness to let go of the old ways, when people with learning disabilities were patients to be treated. When challenged, she said that the drip stand was for hanging hats on, but she, and it, were soon gone.

In 2005 a former resident of Fieldhead made this statement about life in her new service for a Choice Support annual report:

"I am a fiercely independent lady and I have lived in my own bungalow since July 2004. Before this I lived at Fieldhead Hospital, Wakefield, for a long time ... I did not like all the rules at the hospital and I wanted to be independent and take control of my own life. I did not want to live with other people and I did not want staff to stay in my house all the time.

I told my staff about this and a meeting was arranged to discuss this with lots of people, including my care manager and doctor. Everybody thought I could not achieve my dream, including me at times, but I have proved them wrong.

I have a support team who are based at Choice Support's office, not my home. I contact them by phone when I want support or advice.

When I lived at the hospital I used to have lots of 'blips' and I found it very hard to calm down. I often said things I did not mean, but I never said sorry. Now I live in the community I still have misunderstandings occasionally but now I calm myself down as I do not like to feel cross. I use lots of new strategies such as going for walks. My 'blips' are much shorter now and I say sorry for the things I have said.

I like the community I live in and regularly go to my local community centre and pub for a drink and a chat with my friends. I no longer need staff to go with me, although sometimes I still ask them to come along. I also attend the community craft club, and I am very involved with my church."



Bev Williamson

Hospital patient

The services in Wakefield are now established and thriving. They recently went out to tender again, and Choice Support was asked to continue managing the services it opened originally, and also to take on those initially set up by other providers.

The third in this succession of recent hospital closure programmes was **Highbury Hospital, in Nottingham**. Highbury Hospital had its origins in the 1834 Poor Law Act and was, for its first 80 years, the infirmary of the Basford Union Workhouse. Through most of the 20th

century the hospital provided general medical and surgical care, alongside specialised mental handicap provision. In 1970, the hospital had 312 beds: 188 for acute medical, surgical, maternity and gynaecological patients and 124 for mentally handicapped patients. The last mental handicap wards closed in 2006, although Highbury continues to provide general health care services.

Compared to the Darenth Park reprovision 20 years earlier, the Highbury closure was carefully planned and sensitively implemented. It was steered by a representative from within Gedling NHS Primary Care Trust, and structured to accommodate two levels of regular meetings. The first level was operational, and included representatives from providers, the PCT, housing and other professionals. The second level was strategic, and concerned with overall planning and resolving blockages and problems.

In most hospital closures the people perceived as being easy to manage are the ones that leave first, with the 'difficult cases' being left to the end. This usually translates to the more able and communicative, or the quiet and pliable, being first out the door, while the complexly disabled and challenging stay to the bitter end. This was the case with the Highbury closure. The resettlement was extended over three phases, with Choice Support involved only in the last. This meant that it was working with people not only with complex needs, but sometimes too the additional burden of an ascribed role in hospital culture.

If hospital staff perceive that somebody is particularly problematic, it becomes much harder for the resettling agency to see beyond this perception. A perception that may well be as much to do with the environment that people have been living in, as any innate personal characteristics. Indeed, some of the people Choice Support was charged with resettling had already experienced failed community placements and had to return to hospital, and were considered by hospital staff as virtually impossible. These negative attitudes posed an even greater challenge to Choice Support, as people who would, in time, become its own employees held them.

These staff, along with many others over the years, were transferred to Choice Support under a TUPE agreement. TUPE is an acronym for the Transfer of Undertakings (Protection of Employment) Regulations, introduced in 1981 and overhauled in 2006. TUPE is designed to protect the rights of employees whose employer changes as the result of a change of ownership or management. It means that employees, and any employer's responsibilities associated with them, are moved to the new employer by operation of law. Including staff transferred during the Highbury closure, Choice Support had, by the end of 2005, taken on about 600 staff in this way. Although there are challenges with any TUPE transfer – inheriting a workforce that might not share your values being one – Choice Support prefers to concentrate on the benefits. Director of Human Resources Mark Ferry lists four: the organisation needs the staff and would not be able to recruit such large numbers from scratch when opening new services; the transferred staff know the service users; they come imbued with an ethos of public service; many of them are qualified. Indeed, many staff that came to Choice Support through TUPE transfers have since been promoted.^{xxvi}

Recognising that the obstacles to successful resettlement were as much to do with perceptions as actual problems with how to support people, Choice Support invested in promoting its values. Lisa Gregg-Herrett, who managed Choice Support's part of the reprovision, worked on the wards of the hospital for two years, serving as the face of Choice Support, and developing relationships. Then, as new staff were recruited, they too were seconded to work on wards before people moved out, working alongside hospital staff who would become their colleagues when the new services opened. This was a risky decision, as these new staff could have picked up the very attitudes and practices that Choice Support wanted to change. But actually, in the end it had three benefits. Firstly, it gave new staff first hand experience of the lives people led on hospital wards (and of the working conditions of their future colleagues). Secondly, it mitigated against what would have been a split between 'old' staff (former hospital employees) and newcomers, which had proved destructive in earlier resettlements. Thirdly, it provided a conduit through which old

staff could share their knowledge of service users' lives, and for that knowledge to be integrated into new service plans. Knowledge that had, in the Darenth Park resettlement, been almost completely lost.

Another contrast to the Darenth Park resettlement was that each person moving out had their own transition plan. What that included depended on the person. For some it meant many visits to their new house, choosing furnishings and gradually becoming familiar with new surroundings. For others, with limited ability to conceptualise a future move, such a process would have been damaging. In all cases, though, efforts were made to engage peoples' relatives in plans for the move.

Drawing as it did on the accumulation of 20 years experience, the closure of Highbury was an altogether happier and more successful process than the closure of Darenth Park. But once each person left their old ward for the last time, they found that the reception awaiting them in the community was not so different. Neighbours still objected, as they did in south east London 20 years earlier, and finding a niche was still hard:

“Becoming a part of the community takes time for people who’ve lived most of their lives in institutions. Being in the community is not the same as being a part of it.”

Lisa Gregg-Herrett

The Last – Orchard Hill

“Almost all of England's long-stay learning disability hospitals have now closed: about 180 people remain to be moved out, including 93 at Orchard Hill, where closure has been delayed in part by two legal challenges.”

The Guardian – January 2007

As this short book is being written, Choice Support is engaged in supporting the closure of the country's last old-style mental handicap hospital, Orchard Hill Hospital, in Carshalton, Surrey. It is scheduled to close by 2009.

Orchard Hill currently caters for about 90 people with severe or profound learning disabilities, as well as complex health and social care needs. Most are aged between 35 and 45 years old and have lived there for their whole adult lives.

With grim symmetry, this final hospital closure comes in the wake of scandals, just as the first ones did. What's more, the details of these scandals are depressingly familiar. A Healthcare Commission investigation into Orchard Hill itself found that institutional abuse was endemic.^{xxvii} Largely, this was abuse founded in ignorance, rather than deliberate maliciousness. As a matter of routine, staff thought in terms of what a person in their care could not do, rather than what they might do. Staff referred to residents, all adults, as 'children' or 'babies', and the notes for one resident said that staff do not require any communication training because the person could not speak. It is an environment where it is impossible for anyone to live a full, valued life.

A report into conditions in Budock Hospital, Cornwall, was even worse.^{xxviii} Published in 2006 after a year's investigation, it exposed a catalogue of abuses including violence, inappropriate use of drugs and allegations of sexual abuse. One man was illegally bound to his bed or wheelchair for 16 hours a day. It was “the worst case inspectors had ever seen.”^{xxix}

Although it is no comfort to the people living there, these scandals serve as a measure of how far services for people with learning disabilities have come over the past two decades or so. The reports were shocking not only for what they said about the lives of the hospitals' residents, but also because they uncovered surviving pockets of practices that most thought had been abandoned years ago.

Conclusion

Choice Support was formed (as Southwark Consortium) as a local, community-based organisation to help a defined group of people with learning disabilities move from a mental handicap institution back to the communities of their birth. Over time the geographical scope of that vision expanded, and the experience gained in that first hospital closure was put to good use in others around the country. Soon all mental handicap hospitals will be closed. Few will mourn their passing, yet debate continues in some circles about the merits of segregating people with learning disabilities.

It is estimated that there are about 3,000 people living in more than 70 'village communities', or intentional communities, throughout Britain. On the face of it these are ordinary rural communities, with clusters of houses, shops, cafes, working farms and so on. But these villages are populated entirely by people with learning disabilities and their support staff. The idea behind such establishments is that our society is so competitive, aggressive, acquisitive and commercial, that vulnerable disabled people cannot thrive, and are almost always left behind. Segregating them, keeping them apart from these all-pervading forces, enables them to thrive peacefully. It is much the same argument as that employed by the founders of the first mental handicap institutions.

The opposing point of view – the one to which Choice Support holds – is that segregation perpetuates an unjust and unequal society. It is a capitulation to the fact that society does not yet fully include people with learning disabilities. And while such intentional communities may offer some benefits – for example, protecting people from crime, and social opportunities with peers – they do so at the cost of taking away from people some basic rights of self-determination. If people are thus disempowered, then it follows that others – people or institutions – will take power over them. And as Simon Duffy, Chief Executive of In Control Partnerships, said recently in a discussion about intentional communities: "institutions should not

be defined in terms of architecture; institutions begin when one group takes control over another.” xxxi

In contrast, the thrust of Choice Support's point of view is that society should be challenged to accept all its members fully, and indeed, that by doing so it can be enriched. Put another way, by denying a section of society its rights we are all dehumanized. Not just the minority group itself, but all of us.

These arguments will continue, but Choice Support will remain on the side of social inclusion. Closing mental handicap institutions was a giant step in the right direction, but people with learning disabilities remain marginalised and disadvantaged in society. There is much more to do.

Many of the people who moved from Darenth Park more than 20 years ago, who were middle-aged or elderly at the time, have since died. Of the 700 or so people Choice Support now supports, many have never lived in an institution, or if they did, then it was for much shorter periods than that pioneering first generation.

Of the four people that lived in the service I managed from 1989 to 1991, two have died, and one lives independently. The fourth is still supported by Choice Support. She lives in a flat on her own with a small support team. She orders her life carefully with the help of her team, as it became clear over many painful years that a predictable routine is essential for maintaining her own sense of well-being. She has a much busier life than she ever had at hospital, and has renewed contact with her family.

Although it is dangerous to make value judgements about whether one type of life is fuller and more rewarding, and happier, than another, especially from a vantage point of relative comfort, it seems to me that the lives of most people who spent many years in long stay institutions before moving into the community, are better than

they would have been if they were still living in hospital. There, they would have slept in cramped, shabby wards with 20 or 30 other people, some of whom they wouldn't have got on with at all. They would have little or no time alone, except when isolated as a means of control. Activity would be limited to whatever was on offer in the hospital, maybe a cleaning job and some occupational therapy at best. Social life would revolve around the occasional patient's disco. Trips to the outside world would have been rare, and always in groups. They would have had few, if any personal possessions, and little or no regular income. Now they have many of the things most of us take for granted to be prerequisites of a comfortable life – their own homes, possessions, some control over what they do and when. They also have a modest income, dedicated support, their own possessions. Many are becoming established in their communities, forming relationships and making a contribution. Their lives are still not all they might be, but surely they are better than what they were.

Afterword

I came to work at Southwark Consortium (now Choice Support) in 1990, on a secondment from the NHS General Management Training Scheme. I had visited an institution in East Sussex called Leighton Lodge and the horror of the place left me with a strong desire to do something to help people get out of institutions and live better lives.

I learnt many things from my time in Southwark. I learnt the value of a strong sense of shared ethics and a commitment to bring about change. But I also learnt how hard it is for people to unlearn the many subtle assumptions that underpin the oppression of disabled people.

Too often we found ourselves moving people who weren't getting along, deciding what was realistic, deciding what was safe or sensible, deciding what was normal. It took us a long time to learn how to start really listening to people, families and communities. It took us even longer to start to really shift power and control to people.

However, Choice Support has been lucky. At every stage of its development it has found leaders who have been self-critical and who have maintained a desire to do the right thing even when we don't always know exactly what the right thing is. We must keep on trying, and if there are no easy solutions we must learn the skills necessary for solving more complex problems.

Today, Choice Support is ready to begin a new stage of its history. It is well equipped to help people who rightly demand more control over their own lives and who want to achieve full citizenship, not to just live in an 'ordinary house'. Choice Support already has experience of helping people to get jobs, manage their own support, buy their own homes, and of working in real partnership with families.

But what is particularly fitting is that Choice Support is entering the next phase of its life by honouring its own history and the dark and complex past from which it emerged. Nothing is more important than

this. The German philosopher, Karl Jaspers, speaking of the Holocaust, said: "That which has happened is a warning. To forget it is guilt. It must be continually remembered. It was possible for this to happen, and it remains possible for it to happen again at any minute. Only in knowledge can it be prevented." But this lesson applies to us too.

We can do many things to make the world a better place. But we must never forget our duty not to forget the mistakes of the past. Personally, I would like to thank Choice Support for never failing to remember and to constantly holding itself accountable for trying to do better.



Simon Duffy

PHD

Chief Executive, in Control Partnerships

May 2008

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Images:

Inside front cover photo: David Slater

Inside back cover photo: Henry Broome

All other photos from the Choice Support archive.

For 25 years Choice Support has been involved in the closure of learning disabilities hospitals in England. Drawing on the testimony of former hospital patients and its own staff, *First And Last – Closing Learning Disabilities Hospitals*, is an honest and critical account of that work, at times disturbing, but ultimately positive and celebratory.

“This book should be read by every person involved in supporting people with learning disabilities or planning services for them. It reminds us in stark detail of the damage we have done in the past (even when starting out with good intentions), the possibilities for change and the resilience of many people with learning disabilities.”

Eric Emerson

Professor of Disability and Health Research
Institute for Health Research
Lancaster University

“Still not enough people know about the appalling conditions that many people with learning disabilities endured in long-stay hospitals in past decades, nor the huge efforts that have been undertaken by so many to end this practice and give those same people an opportunity for a fuller and richer life. This moving, important and balanced book tells that story from the point of the view of the people who were there, and is a welcome reminder that progress can be made if enough people want it and are prepared to work for it. The tragedy is that it has taken so long.”

Su Sayer OBE

Chief Executive
United Response

“**First and Last** is a book that tells a story that needs to be told, and it tells it with passion, accuracy and a flair for engaging the reader. At the heart of this story are people whose voices need to be heard and whose lives need to be turned around.”

Lord Adebawale CBE

Visiting Prof Lincoln University
CEO Turning Point