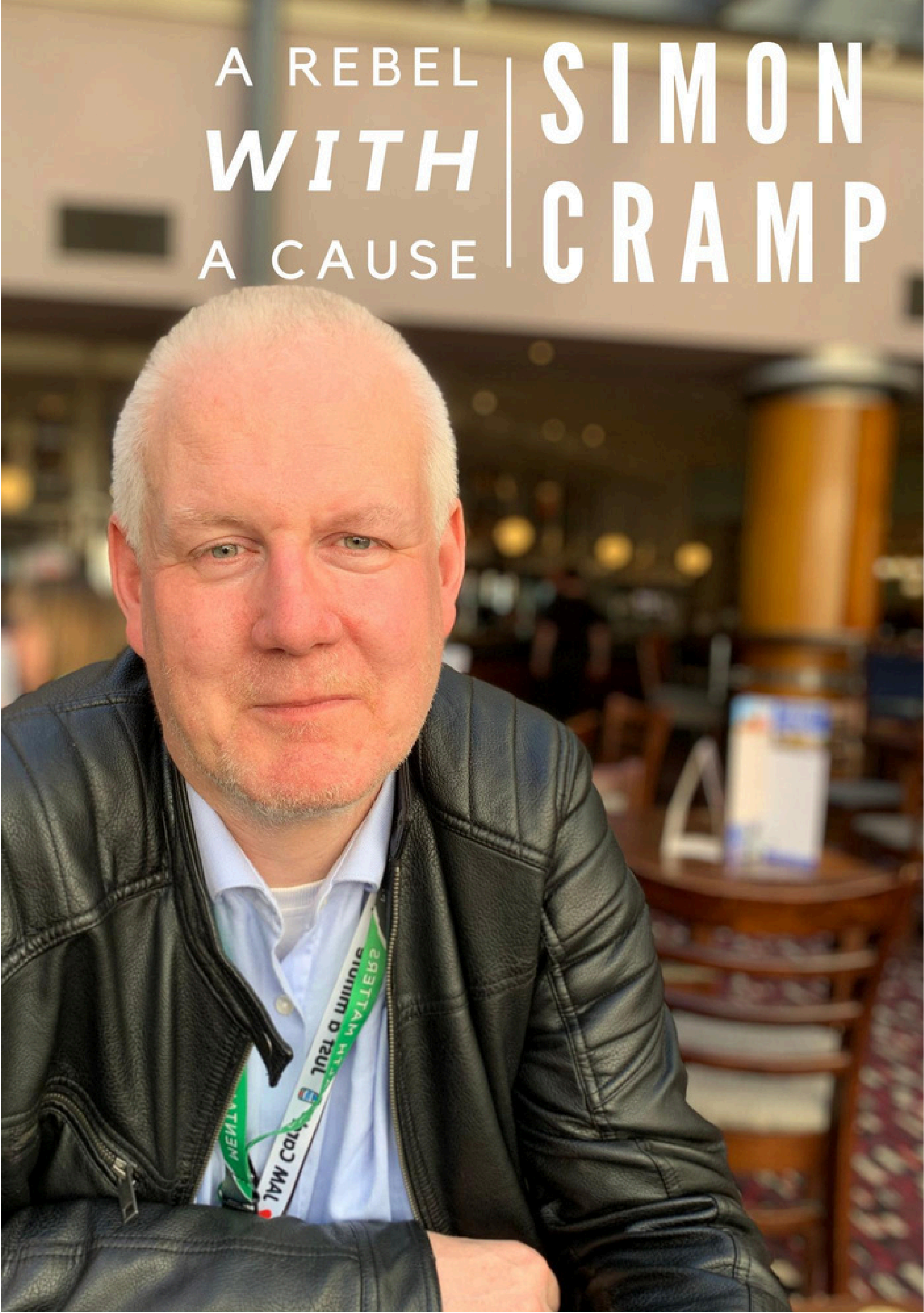
A REBEL *WITH* A CAUSE

SIMON CRAMP



A Rebel with a Cause

Stories, Writings and Reflections

– By Simon Cramp

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Preface

Not many people write a book; here's my second. After 'Don't Cramp My Style', I felt there was more to be said. Anyone who knows me will accept there's always something else I want to say!

Since my first book was published, a lot has happened. We've had COVID, numerous Prime Ministers, a change in Government, and I've had my own health problems. So, this second book has some new writings, more history and some things I wish I'd included in the first book.

Simon Cramp – May 2025

Here I am again, in the rollercoaster of Simon Cramp's life...it has been great fun pulling this together. We've pulled this off mainly by email, text and phone, but have managed a couple of face-to-face meetings. It is always great to spend time with Simon, funny, warm and uncompromising. A ‘fixer’ using his many connections to improve things for others, during the development of this second book he’s advised me on mobile phone contracts, offered to solve a few little glitches with the CQC, and kept me going with Newcastle Brown Ale.

Here’s a mark of how respected Simon is and how much perseverance he shows – in a time when most people struggle to see a GP – I’d arranged to meet Simon in York to edit a draft of this book…then a phone call: ‘Hello mate, can you meet me in Harrogate instead? I’ve got a meeting with the CEO of Harrogate District Hospital…’

Simon tells me, following his recent health problems, ‘I’m slowing down and picking my battles’ Look out.

Tim Keilty - May 2025

Foreword - Sam Clark

Chief Executive, Learning Disability England

Simon was one of the small group of people made lifetime members of Learning Disability England when it was founded in 2016. So, of course, he told me we must meet as soon as I was appointed to my job at Learning Disability England in 2018. I think I hadn't even started, and we had a date to meet. We met for him to offer his support, share his ideas, and I think, if we are honest, for him to check if I was doing the right thing. That positive proactive action on something he cares about is what Simon shares in this book – stories of action on rights, challenging systems that exclude some disabled people, and offering solutions are all captured here. The successes of positively working with his local NHS are set against his own health problems, experiences of Covid, and other hard times. Despite all the challenges, you are left with examples of what can be done to make change happen; as demonstrated by Simon, who continues to speak up for inclusion and fairness.

Most strikingly, I think, is the demonstration of how Simon is a ‘World Class Networker’. He is one of the best-connected people I know, and many of those people contribute to this book, sharing how they have worked with Simon and the difference he has made. It is a great collection of stories about making alliances to achieve more together.

Simon continues to offer ideas and connections to Learning Disability England as well as many other organisations, always wanting to use his anger or frustration to make a difference. He is also the first to ask me if I am okay, or if he can help me out. You will see his continued passion and care for other people in this book.

Family History

Howard Cramp

Simon Cramp – Family History

We all come from somewhere, not only geographical, but also ancestral. Simon is the same as everybody else.

Geographically, Simon was born in Lambeth Hospital, London. This is just off the Elephant and Castle and was one of those old Infirmaries. It started its life as a Workhouse, one of its most famous residents was Charlie Chaplin. When Simon was born, Lambeth was part of the Guy's Hospital Group, and was quite old fashioned.

Simon is an identical twin, his younger brother sadly passing away some 8 years ago.

Simon lived with his family just off Brixton Hill, South London. If you wanted to be a bit posh, you'd describe the location as near Streatham! When actually it was just up the road from Brixton Prison.

The family relocated to Forest Hill, South London before moving up to Derbyshire when Simon was about 2 years old. That was a journey; Mum, Dad, and four children crammed into the cab of a hired truck, with two seats, on a cold winter’s day.

Simon’s ancestry is quite diverse and can be traced right back to the 16th Century. To try to explain all this would take a book, so there are many generalisations to follow.

On his maternal side, little is known, however what we do know is that his Grandad came from Northeast London and spent time in the Army as a boy soldier. Grandad couldn’t really remember much about his family, and we couldn’t trace anybody, as the birth records had been destroyed by enemy air action during World War Two. It is suspected that his Grandad was an orphan and had been brought up in institutional care before going into the Army.

Simon’s Nan was born in East Yorkshire and lived with her ‘Gran’ before being sent into service in her early teens. Enquiries revealed that her ‘Gran’ was what is now referred to as a foster carer. She spoke of the ‘service’ being quite spartan, and on a visit by her employers to their London home, she ran away. She met her husband, and they seemed to have a reasonably happy marriage until Grandad developed Dementia and became quite difficult to look after, before moving into residential care until his death. Nan remained in London until her death in the late 1990’s. The couple had two children, Simon’s Mum and a boy, who emigrated to Australia at age 16 years.

His paternal history is quite well known, but complicated. His Grandma was the youngest of 13 children, 11 of whom survived into adulthood. The two boys who did not survive, one dying in early years, the other dying in the Spanish Flu Epidemic. His Great Grandad was born in South Devon, and came from a family of agricultural labourers, being sent to London by the local Poor Law Commissioners following an agricultural slump. The family initially lived in the Paddington area, but later spread out over North London.

Simon's Paternal Family

taken in 1948, well before he was born.

Great Grandma was born in Dovercourt, Essex, and moved with her parents to North London when her father was employed as a Farrier. Great Grandpa and Great Grandma met, and later married, spending their lives together in one small area of North London. They lived in a two bedroomed terrace house, and the family story is that when some of the children got old enough to manage for themselves, the family lived in two such two bedroomed houses; parents and younger children in one and older children in the other.

'Trigger'

Great Grandad worked in a variety of low paid jobs. A family snapshot shows him as the local parish road sweeper, hence he is generally referred to, these days, as 'Trigger'. He also acted as caretaker for a local church and helped run a British Canteen during WW2.

Great Grandma died in the late 1920's/early 1930's. Simon's Grandma was always described as a character, strong in opinions and her belief in herself. Following the death of her mother, it was planned that she would be sent into service, a situation that never happened because she made it plain that this was not what was going to happen!
She worked at Standard Telephones, constructing and wiring telephone exchange equipment. Simon's Grandpa was born in Maidstone, Kent, one of six children.

Great Grandad worked for the Post Office and is reported to have been a local Councillor. Great Grandma looked after the family. Grandpa was very good with numbers, and after leaving school, worked as a sorter in the Post Office, before sitting the progression examination and moving to the Post Office Accounts Department. He then moved to London and lodged with a relative in North London where he met Grandma. Grandma always said that she let him chase her for a long-time before allowing him to catch her.

Grandpa’s family history is interesting. Originally (late 1700’s), the family came to England from Germany, fleeing religious persecution. They settled on the Sussex coast, eventually spreading out over the Southeastern corner. Upon arrival, the family name was anglicised. Some of the family moved on to America. One story that has emerged is that a male relative became the Churchwarden for a church in Sussex. He was later sent to prison after money was missing from poorly kept accounts. The press report of the incident states that the convicted person was both illiterate and numerically challenged but was responsible for keeping proper records (?).

Simon’s Grandparents married the day WW2 started, and we have always blamed them for the conflict! Grandpa’s job was evacuated to Yorkshire, so the couple moved ‘oop north’, settling in the Harrogate area. They had just settled when Grandpa was called up into the Army and was sent to Catterick Camp. On arrival he was ‘asked’ what his civvie job was and he replied, ‘I worked for the Post office’ ‘Great’ said the Sergeant, ‘you’re going into the Signals.’

After completing basic training, off he went to the Royal Signals Depot. So what do you do with a Soldier who can’t drive, can’t do Morse code, and is not very practical? That’s right you promote him to Sergeant and put him in charge of a Radio Truck!

He saw service in Egypt, Italy, France and Germany. He always said he was a few days behind any fighting and that suited him fine!
He did speak of one incident where his radio truck got a bit lost, whilst in Italy. They drove into a small town near Rome, and coming in the opposite direction was a German army truck, both trucks did a smart about turn and returned to their own lines. After the war, he never spoke of his experiences, never wore his medals and never attended a remembrance parade, all he wanted was to forget the whole thing.

Whilst living in Harrogate, the couple had their eldest child, who was always told he was born at Knaresborough Hospital. Grandma always said the hospital was very posh, and would tell everybody he was born in Knaresborough. A few years ago, their eldest son, curious about where he was born went up to Harrogate, and found that there was no such hospital, but he had been born in Knaresbouough Road Hospital, Harrogate, which was an old poor law infirmary, that was then a housing estate. Shortly after his birth, and Grandpa being called up, Grandma moved back down to London, to be near the family, so we have a relative eligible to play for Yorkshire Cricket Club, with a real London accent. He is really proud to be a Yorkshireman!

A few years later the couple had a daughter, and her first memory of her Father, was being taken out of bed in the middle of the night and being sat on a strange man's lap, she didn’t like it because his clothes were all scratchy, it was his army uniform!

After the end of WW2, Grandma and Grandpa lived in a rented house in North London, close to Grandma's family home. They had one other child, a boy, Simon's Dad. He was born when Grandpa was back from the army and was always thought of as Grandpa's favourite. Life followed a pattern of Grandpa going off to work at the Post Office Headquarters in the City of London, Grandma organising the children going off to school, and taking no excuses for non- attendance. Illness was not an excuse, Simon's Dad telling his Mum that he really didn't feel well, but was packed off anyway, and within days the whole school was down with German Measles! Every year would be a holiday on the Kent Coast, outings to family, now spread all over the place, scouts, guides, youth clubs, and Sunday school.

Their children all had bikes, and if they wanted to go anywhere 'on your bike' as it didn't cost anything. Grandma and Grandpa saved up and bought a house, with a 'garden', Grandma thought she had arrived! The family situation remained the same, just relocated.

In the early 1960’s, Grandpa was told that his job was moving to Derbyshire, as part of the then government moving departments out of London. He had steadily gained promotions in his job and was going to get another on moving. Grandma was, to say the least, not keen on this, but the move took place, into a brand-new house, on a new estate with green fields and the Peak District not far away.

This still did not change Grandma’s mind, she had to move away from her home area, and her family, and she was not disposed to enjoy her new situation. She did not have a conversation with Grandpa for some months,and then, one day, he sat her down and told her that he had to stay, but he would buy her a house back in London, and he would visit every other weekend. She thought about this and then replied,’I’ve been married to you for many years, and we’ve never really had a lot of spare money, we’ve managed OK, so now we’ve come to live here, and you’ve had a big promotion, and a big wage increase, If you think I'm going anywhere without you, you are very much mistaken, I'm going to stay here with you and help you spend your money.' After a few minutes they both began to laugh, and everything was back to normal.

Neither Grandma or Grandpa could drive, but the day after this conversation took place, they went out booked driving lessons for Grandma and bought a small family car. She did help him spend his money, and he was happy to let her.

Simon's Grandma, as described, was very strong willed and 'always right'. Nevertheless,
she was well loved by the family and was always there when needed. She was a fabulous cook, with a tendency to overfeed everyone. An invitation to Sunday lunch was lovely, with a full roast followed by at least three sweets. She was a really good driver and would often drive all over the country visiting friends and family. She never had large cars, usually small hatchbacks, and as arthritis

made gear changes uncomfortable, she moved to automatic gears.

One particular day she was travelling down the M1 motorway to visit her sister who had been admitted to care after developing dementia, she was travelling along, when a big car with blue lights stopped her in South Derbyshire. She had been doing nearly 90mph. Luckily, she received a stern warning, and off she went; only to be stopped in Leicestershire and Bedfordshire for the same thing. Simon’s Dad, who was with her, immediately took over driving!

Grandpa continued to work for the Post Office, until at age 61 years, he decided that there was more to life. He had things he wanted to do. One wish he’d always had was to open a bed and breakfast place near his birthplace, another was to visit Rome, a place he visited very briefly whilst in the army. He chose to retire, but shortly after, he fell ill, and was admitted to hospital. He was found to have a brain tumour and died some weeks later. Grandma was devastated, not only by the loss of her much beloved husband, but because he'd always managed the money. She didn't know how to write a cheque! Grandpa used to say that she was the head of the household, whilst he was chair of the fundraising committee!

Grandma continued to live in Derbyshire, despite her earlier reluctance to move there, enjoying visitors, and the family. Her health began to deteriorate with her age, and following a road accident, that was not her fault, her car was written off by the insurance company, she was persuaded not to drive any more. She was lost without her car, and was reliant on friends and family, something that was completely alien to her. She had always been the one to help others, now she was the one that needed help. In 2007, she was found to have a cancerous growth on her face, and this was removed leaving her temporarily scarred. She had always been very particular in how she looked and didn’t ever leave the house without a bit of ‘lippy’.

Nobody was sure exactly why, but she decided that if she couldn’t be in total control of herself, then life wasn’t really worth living. Over a short period, her health deteriorated, her mobility suffered, and eventually she, kicking and screaming (metaphorically), went to live in a care home. That did not improve things, and she chose to stop eating. One day her children went to visit, and she told them she had had a lovely night, and all her brothers and sisters had visited her. They had all by this time passed away, she said that they had come to collect her, and a few hours later she passed away. She remained in control of her life to the very end. She had planned her funeral service, choosing the hymns, the readings and, most of all, wanted to be carried into the church. On the day of her funeral, the weather was not kind, it rained. However, the family chose to walk from her house down to the church, not a long way, but far enough for everyone to get soaked.

Somebody joked that Grandma should have ‘a word’ and get the rain stopped, and, as if by request - the rain stopped - and the sun came out. Upon reaching the church, and with everyone inside, down came the rain. The undertakers bought out a coffin trolley, and they were persuaded to carry her, as per her wishes. Grandma was a strong willed, capable, determined woman, and much loved for being who she was. She was extremely proud of Simon, and how he had achieved things in his life, despite his difficulties. Simon’s Mum and Dad met in London and were never really apart from then on. After the birth of Simon, and his twin, they knew there had been problems at the birth, but were never actually told that this may result in difficulties later in life. The twins development was delayed, not walking and talking until nearly 3 years old. The twins talked to each other in their own little language, they had names for their Mum and Dad, these being Ning and Nang, and if they wanted Ning, and Nang responded, all hell broke loose!

They were loved by their whole families, and everybody got stuck in.

Being identical, they were difficult to tell apart, especially from behind. Usually, identification was by watching the way they moved, or their little traits. One real giveaway was that Simon liked to wear blue colours, and his twin red, and that was strange given Simon’s political leanings of these days.

When Simon was about 6 years old, his Mum started to show symptoms of tiredness, and discomfort in her arms and legs. Following tests she was diagnosed with multiple sclerosis. Following diagnosis, her physical health deteriorated quite rapidly, but being who she was, she fought back, determined to beat this crippling condition. She never beat it, but did give it a good battle. In the early years of her diagnosis, her health deteriorated quite quickly, but she decided that she wasn’t having this, and chose to go to the local college to get some sort of certificate. This was so that she could feel that she had achieved something. She did manage to get typing, and office administration qualifications, but the main thing she always said that she was most proud of, is that she helped make the local college ‘disability friendly’ by working with the facilities management to provide the necessary changes.

Following college, she worked at a local mobility charity, before going to get some ‘interview practice’ with the local library service. She was offered the job and helped to make local library services accessible. Sadly, MS being what it is, her ability to manage deteriorated and she had to retire under poor health. She was beginning to suffer with a number of other ailments, high blood pressure and her legs developed skin problems resulting in ulcerations, and the Dermatologist she saw at the local hospital, who prescribed the most foul-smelling ointment, something she decided was ‘not for her’. She went onto the internet and found information regarding magnet therapy. The items were purchased and used. Within weeks, her ulceration had disappeared, and when she went back to the hospital, the dermatologist pooh-poohed the magnets, but was unable to explain why the ulceration had gone away. No more visits were made to the hospital for that problem, and the ulceration did not reappear. The high blood pressure was somewhat more problematic.

She was treated by the local GP, who kept changing the medication when one did not work, and despite requests did not refer her to the hospital. When after 3 years he did refer her, the consultant was unable to help as the failure to treat properly had meant that her kidneys were virtually non-operational. There followed a number of years of dialysis, a treatment that she found hard and painful. Dialysis staff were fabulous and kind, but eventually in 2008 she became quite ill, and passed away within a few days. Simon’s Mum was another strong willed, determined, and capable woman with a good sense of humour, who despite her considerable physical impairments, fought all corners until eventually not being able to carry on.

One instant of her sense of humour was when visiting the local Tesco Supermarket, there was a notice stating, ‘PARKING FOR THE DISABLED’. Simon’s Dad suggested that he leave her sat in the parking area supplied for her! loads of laughter ensued, and for the remainder of her life she would often refer to herself as a ‘THE’.

Simon’s Dad was a post war baby, born in Hampstead, London. He was born prior to the beginnings of the NHS, and came into the world at a Maternity Home, funded by a charitable group; the patron of whom was our late Queens Grandmother. He was quite a large baby, and one day the Patron was visiting the home. Apparently, she was a great knitter, and she used to knit cardigans for the babies at the home. The only one that fitted Simon’s Dad was a purple one, but it had to be worn for Her Majesty. He was not an academic child, and his school reports are filled with ‘Could do better’ and ‘must try harder’, but, in his defence, this was a time when jobs were aplenty and there was low unemployment. If you didn’t like the job you had, you could leave and by the end of the day, have another to go to.

Like most boys of the age, he had a number of before and after school jobs; paper round in the morning, and delivery boy for a local grocer and hardware shop. He used to have to ride a delivery bike, just like Granville, in Open All Hours (BBC tv 1976 - 1985).

First, he'd take out the grocery orders and then take out big drums of paraffin to customers. The bike was a nightmare to ride, very heavy, and with two 5 gallon drums of paraffin, incredibly unwieldy. He later had an after school, and Saturday job, selling evening papers outside an Underground Station when London had three evening papers: Evening News, Evening Star, and Evening Standard.

On Saturdays you also had the Pink ‘Un, with all the sports news. He had to call out his wares ‘ Evening News, Star, Stand-dard’!. He carried on with that job until he left school. He was a member of a local cub, and later scout group. There he is centre front row, with his trademark, he always had his sleeves rolled up!

Every year from Easter to September, off he’d go with the Scouts on camping trips, once a year for a fortnight by the sea, and the remainder to the local site. This entailed helping to push or pull a trek-cart full of Blacks Niger Tents, and equipment about 5 miles from the Scout Hut to Camping Site, up hill and down dale. There was no option as nobody had motorised transport.

School summer holidays were always sunny and hot, or so memory says, and nearly every day was spent at the local open air swimming pool, entry 3 old pence, a pack of sandwiches, and a bottle of water, what more could a boy want. He left school at 15 years old and went to work for the Post Office. He really wanted to be a GPO Telegram boy, but by this time he knew he’d be moving out of London, so it wasn’t really an option.

So, he worked in an office, moving the Derbyshire in 1964, when he was 16 years old. Shortly after arriving in Derbyshire, he got a motorcycle, a Royal Enfield Ensign, 150cc, 2 stroke machine. Very similar to the ones he wanted to ride for the Post Office, with metal leg guards, but green in colour rather that GPO red.

Not being very office inclined, he joined the Police, as a Cadet and the Constable, returning to London in his early 20’s. Leaving the Police shortly after the birth of Simon and his twin, he started work on the Ambulance Service. Lack of accommodation brought on a transfer back to Derbyshire, and this was a job he really enjoyed, albeit the wages were pretty dire.

With a growing family, a move into the Insurance Industry happened; a job he never liked, and after some time, he started work in the Social Care Sector, a job he realised was just what he was reasonably good at. Juggling his full-time job, and his caring role within the family was not always easy, and he always felt that he, perhaps, did not always give the family the amount of care they needed. Throughout his working life, some of his employments did test his feelings. He openly believes that some of the deficiencies in human nature, and the things people did to each other, left him protecting himself from harm through a rather strange sense of humour. The hurt and anguish of others did not always affect him as it should, but this was his self-protection.

Dad was often imperfect in what he did, but he tried his best. He was not always tolerant as to the views of others, usually when his experiences clashed with others theoretical interpretations of situations. He had great regard for many of his supervising managers, but often found himself in conflict with those managers who really didn't understand the practical application of working practices. Simon has a step-sister, who is older, married with two children. Sadly, his younger brother passed away in 2022.

As you will recall, Simon is an identical twin. His twin sadly passed away some years ago, leaving Simon absolutely distraught and effectively losing part of himself. His twin also had learning difficulties caused by lack of Oxygen during birth. Simon talked about his twin in his previous book, focusing on how much he missed him, so all we will look at here is some of the things that made him unique.

He found people difficult, he always could not understand why he was subjected to taunting and name calling from others. He could make friends, and once made, that friend was well treated and respected.

Most of the people that engaged in unpleasant behaviour towards him, can only be described as ill educated, discriminatory and ridiculous. Not only his peers, but also some adults.

He was always better with animals than he was with people. On his school work experience placement, he went to a dairy farm, and at the end of the placement, the farmer wanted to keep him because he could get the beasts to do whatever he told them. The family also had a variety of pet dogs, which absolutely adored Simon's twin, following him around wherever he went. One of the dogs, a cross between a Rhodesian Ridge-back and a Belgian Shepherd, weighing in at some 9 stone, was a particular favourite. He was very handsome, and extremely clever.

This dog was often taken to work by Simon's Dad and would often be instrumental in gaining the trust of children, who would share their stories with him, with Dad frantically writing notes. On one occasion, after a boy had disclosed his situation to the dog, who would sit there with his head moving from side to side, and his enormous ears twisting. The dog's role was discussed in a Family Court, with the Judge requesting the dog attend court. The following day, the dog attended court, and sat listening to the Judge, doing the head and ear movements.

The Listening Dog

Simon's twin was very sporty, loving football and cricket. He put his heart and soul into playing. When he left education, he gained work under a sheltered employment scheme in Sports Centres. It was found that he couldn’t swim but was taught by one of his colleagues. That led to a whole new experience of life for him, leading to inclusion into Special Olympics, representing his region and GB. He also funded himself to gain a swimming teachers qualification. Over his lifetime, Simon has lived in a family that always accepted him for who he is, they have supported him in his endeavours, and encouraged him to be what he is.

Simon has been exposed to experiences within his family of disability, turmoil, joy, sadness and great loss. It is no great surprise that he does what he does. He will not be put off by spurious arguments, or by organisations saying that this is our policy, despite that policy not taking into account disability…He has a wide range of experience, that can be invaluable to others.

Don’t Cramp My Style (Revisited)

Seán Kelly and Simon Cramp

Small Victories, Big Difference

https://www.cl-initiatives.co.uk/small-victories-big-difference/

It’s not about being angry – it’s how you use this, says Simon Cramp, reflecting on his work to improve the lives of people with learning disabilities. Seán Kelly meets him.

'I hope it's a book that is not just about how good I am - I hope it is also about changing government policy by making small victories with a lot of help from other people,' says Simon Cramp a self-advocate and campaigner and for people with a learning disability.

While the title of Cramp's book, Don't Cramp My Style, is an amusing pun, given his life and his passion to create positive change, it is difficult to imagine anyone managing to cramp his style in any way. The book tells Cramp's life story, setting it against the backdrop of policy developments and scandals in the UK that affect people with learning disabilities. Cramp wrote it because he had been disappointed on reading Alastair Campbell's diaries covering his time in the Blair's Labour government. 'It was all about him,' he says, and did not cover wider developments sufficiently. The story starts with his birth in 1971 as one of a pair of twin boys. Neither brother started breathing soon enough after the birth which led to them both having learning disabilities and various health problems. Simon's brother Adrian's learning disabilities were 'a bit more severe'. Because of this, Cramp has dedicated much of his life to improving matters for people with profound learning disabilities. Adrian sadly passed away about three years ago, but his

older brother (by eight minutes) has continued as a committed campaigner. As he grew older, Cramp became involved with the local Mencap group. He first came to the attention of National Mencap at the organisation's conference in 1998 aged 27 when he made an impassioned speech in favour of people with learning disabilities having voting rights within the organisation. He cannot remember his exact words: "Forgive me Sean - it's nearly 20 odd years ago - but it was something like: 'If you don't give us the chance that we can do this, how will we ever know whether we can?' "
He spoke from the heart with passion and clarity, and the effect on the conference was electrifying. When the vote was taken, the huge majority needed for the rule change was achieved. There was uproar, Cramp says. A photo of him, eyes closed and punching the air, surrounded by supporters, went across the world.

'I did a You and Yours radio interview, I did the Guardian, I did most of the national newspapers and my picture appeared even in Australia and places everywhere around the world. It went global. You know - "charity gives a voice for people with a learning disability".' Not surprisingly, he soon found himself voted onto the national assembly and then the board of trustees. For a self-advocate, he describes this as being like a footballer who suddenly finds himself in the premier league.

'It's quite a big leap. Once you get into those positions it's not about 'What are your problems?' You are there to do a job for other people because they have elected you and it's a completely different ball game,' he says. The position at Mencap led on to Cramp becoming a member of the Royal Society of Medicine Intellectual Disability Forum. He says his biggest honour there was being asked to chair a symposium for the society at the House of Lords. Other red letter days that feature in the book include going in top hat and tails with Lord Rix of Mencap to St Paul's Cathedral to celebrate the Queen’s Mother's 100th birthday and being called to 10 Downing Street to meet Prime Minister Tony Blair. The book includes numerous positive tributes and testimonials from people he has worked with. 'Perhaps I am blowing my own trumpet for some of it,' he says. However, he adds: 'You can't do campaigning all on your own. If you are the lone voice, then people at the Department of

Health & Social Care and other government departments don't listen to you.' He is keen on sophisticated campaigning methods: 'The days of chaining yourself to a government building are long gone. You have to be a bit smarter.' He is delighted to have been described as a 'world class networker' by Alicia Wood, the former chief executive of Learning Disability England (when it was Housing and Support Alliance), and others. One absence in the book is the voice of other self-advocates, Cramp explains - 'Unfortunately, I didn't quite get to speak to any self-advocates because they were in different parts of the country, and I have lost touch with some of them. That was one of my downsides'. He points out, however, that they are mentioned in a contribution to the book written by Don Derrett, a pioneer of self-directed support, who worked with him at Mencap.

Elsewhere in the book, David Wolverson, the former chief executive of Dimensions, writes: 'When you take even one step in Simon's shoes, I wondered how he had not become an angry young man.' To this, Cramp responds: 'I became an angry man! But it's about how you use it.' He tells of being at a meeting years ago at the Home Office. 'I was getting quite angry and quite bolshy, and at times bordering on being rude because I was still learning my trade,' he recalls. He quickly caught on that he would not be invited again and so he learned to be more professional in his criticisms.

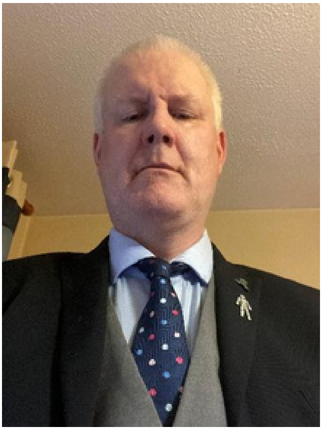
Making the law

Cramp is particularly proud of having been involved in the development of the Mental Capacity Act 2005. With others, he successfully campaigned for the inclusion of advocacy including the requirement for independent mental capacity advocates. Mental capacity continues to be a concern for him.

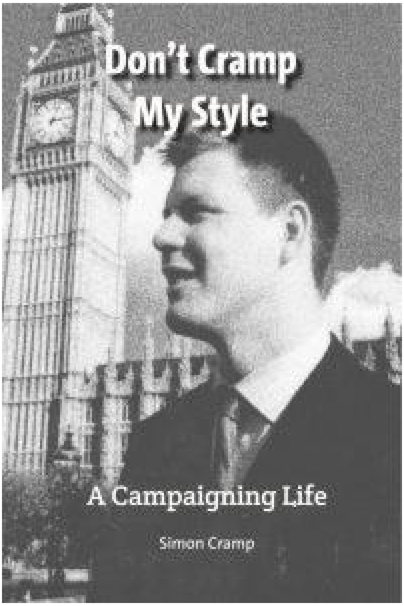
'That's one of my babies. That is one of the things that I am so passionate about. I will fight you to the end in debates and try to make you see my point of view [over mental capacity]. I don't care who you are - whether you are a doctor or whatever,' he says. He finds it amusing that the act was nearly invoked in his own case. He was in hospital for a CT scan and the doctor was going through the checklist before the procedure. He was having one of those days where his dyspraxia made it hard to process information and he had trouble understanding one of the words. When the physician began to question his mental capacity, Cramp derived some satisfaction from saying: 'I beg your pardon. I was one of the people that made sure that act actually happened.' A hero and inspiration is 'bless him, Brian Rix'.

The late Lord Rix - an actor in saucy stage farces that were popular in the 1950s and 1960s - is well known as a founder and chair of Mencap.

Rix was a classic 'luvvie'. Whenever Cramp met him, Lord Rix used to say 'Hello, love, are you alright?' and, if Cramp needed help with something, he would always say: 'Yeah, love, leave it with me.' Rix's willingness to drop what he was doing to help Cramp probably caused 'a few narked faces on Mencap senior management'. 'I just loved him to pieces - as a bit of a father,' he says. In turn, Cramp helped Rix manage a difficult situation in the House of Lords, by suggesting that some tricky and confusing amendments to a bill were withdrawn and rewritten. Rix took his advice and Cramp is proud that he was able to help him in return. He is also proud that Rix's son Jonty has written one of the forewords to the book. Another of the forewords is written by Guardian correspondent David Brindle. Cramp is amused by Brindle's approach: 'I think David puts it nicely when he says this is quite a disorganised book, but, if you want a scholar's thing, an academic book, then don't buy this book. I think it's perfect, you know.' In truth, it is an unusual and very personal book - and it strongly reflects the character of its author and central figure.



Towards the end of the book, he half- jokingly suggests that, maybe, one day he will become 'Lord Cramp of Chesterfield'. This comment says a lot about him, displaying his sense of humour and his undeniable ego, as well as his dedication to public service. It is almost impossible not to chuckle at his cheek but, on the other hand, a seat in the House of Lords might suit him very well indeed.



Don't Cramp My Style: A Campaigning Life can be downloaded as a pdf or purchased as a hard copy from Citizen Network.

Sean Kelly was chief executive of the Elfrida Society from 2001 to 2012 and is now a freelance writer and photographer.

New Writing

Simon Cramp

Being in Hospital Campaigning for Better Support

Being in Hospital with copyright permission by Chesterfield Royal Hospital, foundation trust, and Simon Cramp.

So, I have done a lot in my life now. For my next journey, I talked about in ‘Don’t Cramp my Style a Campaigning life November 2017' by The Centre for Welfare Reform. I’ve done some amazing stuff; worked for OFCOM, and with

Department of Health, alongside other departments; advising and getting the best deal for all people with learning disability. I helped my local hospital create a hospital passport in Chesterfield. That’s in beautiful Derbyshire for those that don’t know it, full of beautiful countryside.

In May 2017, I was in hospital because I thought there was something wrong with my heart and they said ‘no’, but wanted to reassure me, so they did a test. I was looked after by an excellent Cardiologist and had a angioplasty, where they test you though a cut through your groin. You are awake, but they can give you a sedative to make you sleepy. They put this dye up you, and if it changes to a certain colour, then you haveproblems. Well, we got the go ahead to fix it but I waited 10 hours without my medication and was in a lot of pain. Anyway, I suggest this patient passport and I will explain in more detail later in the book how it develops. The experience was a real buzz, and I realized it could benefit me. The next day, I thought about how this could help with learning disabilities on a larger scale. I left the hospital that day, grateful for the incredible staff at the Royal Hospital in Chesterfield and the broader NHS. I work with Public Health England and advocate for patients' rights, proud of my achievements, but recognizing there is more to do. Here is part of the blog originally published by NHS England on their website on 5th September 2018. Here the essence of the blog – about my Patient Passport. “It includes the ways a person likes to be communicated with and other things staff need to be aware of. It fits easily into a pocket or handbag and is an easy-to-use reference it’s intended to guide health professionals during clinical discussions with patients that go beyond what is included in a person’s medical record.

The passport asks about things like what people think they are taking medication for, do they need glasses, how they normally behave and it's all about helping people with autism, a learning disability, mental health or sensory problems. The book stays with the patient and can be added to the red bag scheme for those people who are being admitted to hospital in an emergency."

Chesterfield Royal Hospital
CHARITY
PROUD TO GIVE, PROUD TO CARE

NHS
Chesterfield
Royal Hospital
NHS Foundation Trust

About Me

Hello.

I like to be called:

Please read this if you are caring for my health.

This booklet will give you important information about me and my health.

It belongs to me and I will need to keep it with me.

This fed into the NHS long term plan that came out by Government in January 2020. The Trust received national acclaim for the introduction of its ‘Patient Passport’. Former patient Simon Cramp helped develop the booklet to help patients with communication difficulties get information across to clinical colleagues ‘at a glance’ before patient notes are accessed. It stays with and can be personalised by the patient and will help recognise patients living with dementia or autism quickly. A YouTube video was produced to explain what not to bring into hospital when admitted as an inpatient. Intended mainly for those coming for a planned procedure, the light-hearted video had a serious message intended to reduce the risk of valuable items being lost, explaining what people should and shouldn’t bring ahead of an inpatient stay and how visitors can support this.

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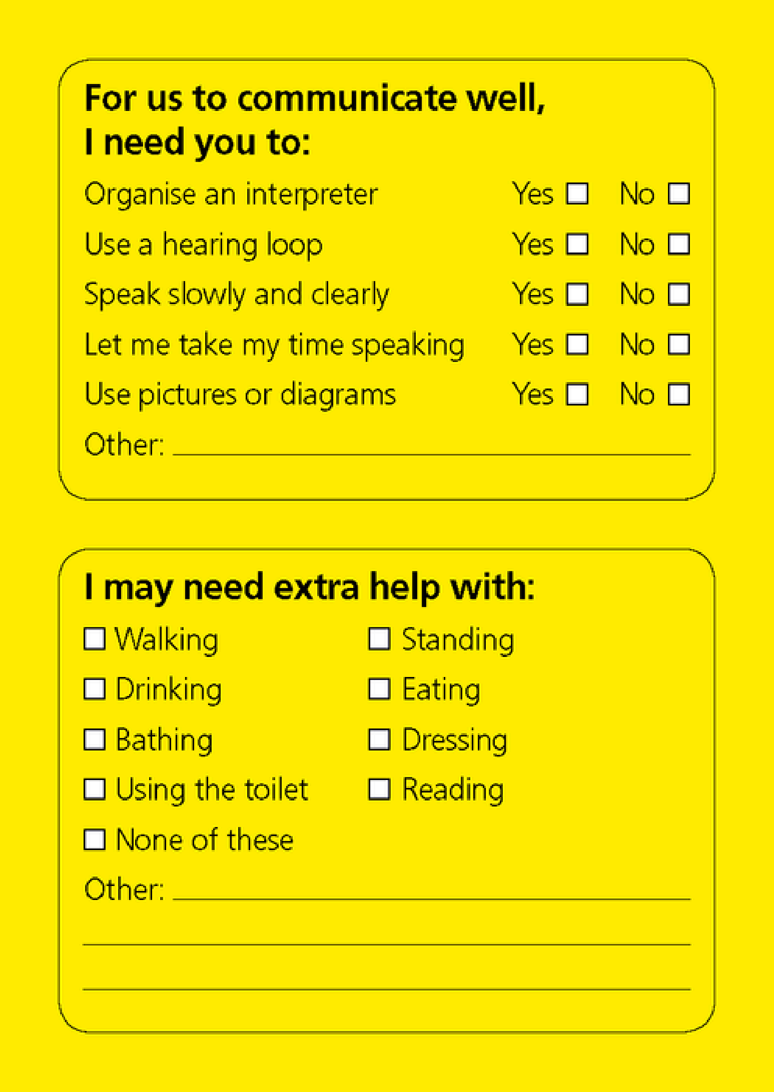
Here are some sections of the Passport.



For us to communicate well, I need you to:

Organise an interpreter Yes ☐ No ☐
Use a hearing loop Yes ☐ No ☐
Speak slowly and clearly Yes ☐ No ☐
Let me take my time speaking Yes ☐ No ☐
Use pictures or diagrams Yes ☐ No ☐
Other: ______________________________

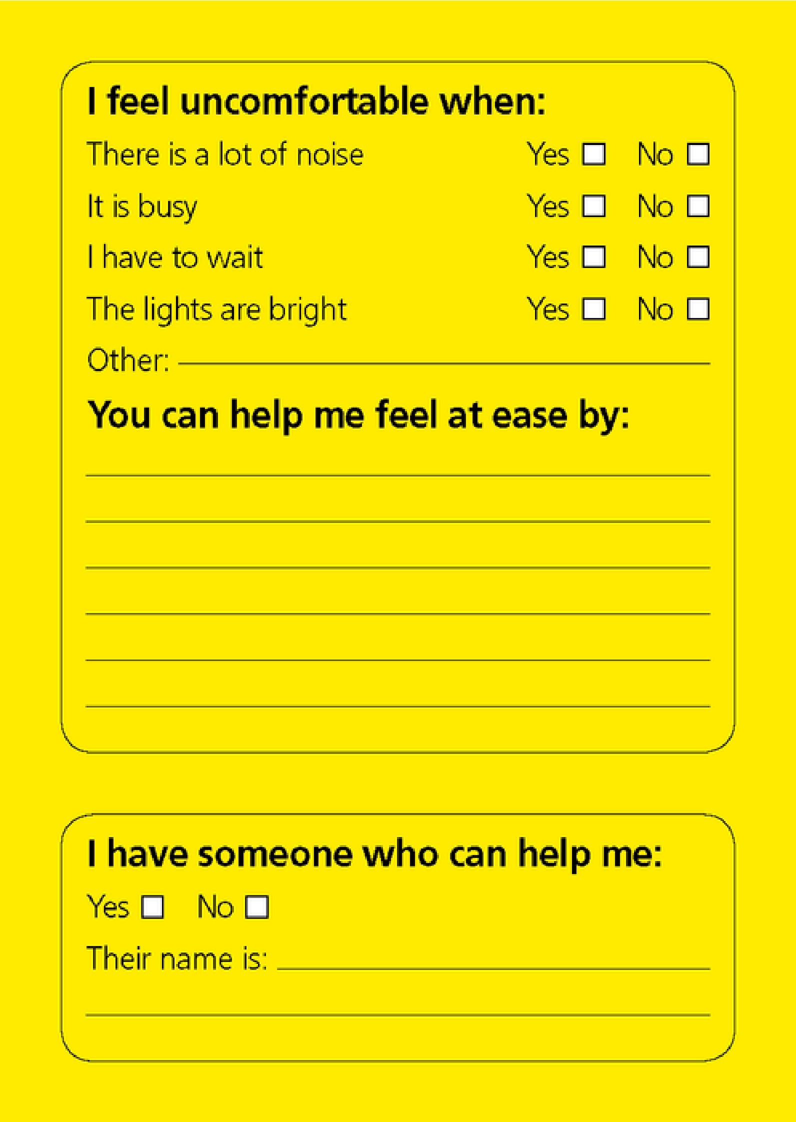
I may need extra help with:

☐ Walking
☐ Drinking
☐ Bathing
☐ Using the toilet
☐ None of these
☐ Standing
☐ Eating
☐ Dressing
☐ Reading

Other: ______________________________

____

____



I feel uncomfortable when:

There is a lot of noise Yes ☐ No ☐

It is busy Yes ☐ No ☐

I have to wait Yes ☐ No ☐

The lights are bright Yes ☐ No ☐

Other: ____________________

You can help me feel at ease by:

____

____

____

____

____

____

I have someone who can help me:

Yes ☐ No ☐

Their name is: ____________________

____

Guide

This booklet has been designed to help you tell us your needs when you come to hospital or see your GP. You should fill in the booklet before a hospital visit or GP appointment – you can ask a family member, friend or carer to help you.

This booklet aims to help you:

- **Talk** to doctors, nurses and other health professionals, rather than just answering their questions
- **Tell** us your most important needs and worries, such as a disability, allergy or the need to have someone you know with you
- **Tell** us the same things less often

This booklet aims to help our staff:

- **See you as a person,** so that you are treated with dignity and kindness
- **Have better information** about your health and needs
- **Talk and listen to you,** rather than only having time to ask you questions

Produced with kind permission and under strictly copyrights not to reproduced without formal permission of Chesterfield Royal Foundation Trust and Simon Cramp to protect the intellectual property rights. We are not trying to be awkward, but this for patients - not a private company who are only interested is profit or glory - this is not what this is about.
I would like to express my thanks to the following individuals from the NHS:

- Lynne Andrews, former Director of Nursing at Chesterfield Royal Hospital
- Sarah Turner Saint, former Head of Communications at Chesterfield Royal Hospital
- Simon Moffat, former Chief Executive
- Angie Smithson, recent Chief Executive
- Jon Cott, Deputy Medical Director, Consultant in ICU, and Lead for the Listen into Action scheme, which assists staff in cutting through red tape to improve patient care and operational efficiency.
- Susan Tower, Patient Liaison Officer and co-originator of the "About Me" booklet initiative.

And thanks to the rest of the senior management team at the hospital, as well as colleagues from NHS Ability and the national team for learning disabilities for NHS England. I have also collaborated with colleagues from NHS England Communications. Without your help and support, this wouldn't have happened. I apologize if I missed someone, but I am grateful for everyone's support.

Contributing to the NHS Long Term Plan

This plan was really important for the NHS and took a lot of effort. Even though I usually don't agree with many of Theresa May's policies, I actually liked this initiative, even if I wasn't invited to the launch—which is a whole other story. The plan was about 150 pages long, detailing what the NHS needed to do. Officially, it covered NHS England, which gets its power from the Department of Health and Social Care. This department sets the policies and overall direction for healthcare.

The Department of Health and Social Care deals with policy and big decisions, while NHS England handles the day-to-day operations and treatments in England specifically. Meanwhile, healthcare in Scotland is managed by the Scottish Government, led by a First Minister, and they're accountable to the voters. Wales has its own powers following referendums and laws passed in 1997 during Tony Blair's time with New Labour, making things more complicated. But this document only covers England.

I teamed up with friends from Learning Disability England and their Chief Executive, who wrote the foreword for this book. We all worked on the NHS long-term plan through NHS England. Learning Disability England helped run consultation events for people with learning disabilities and autism, as well as professionals and leaders in the third sector. The aim was to gather everyone's views to help shape the plan, which was wrapped up in January 2019.

Blogs

A Patient Passport That’s All About Me.

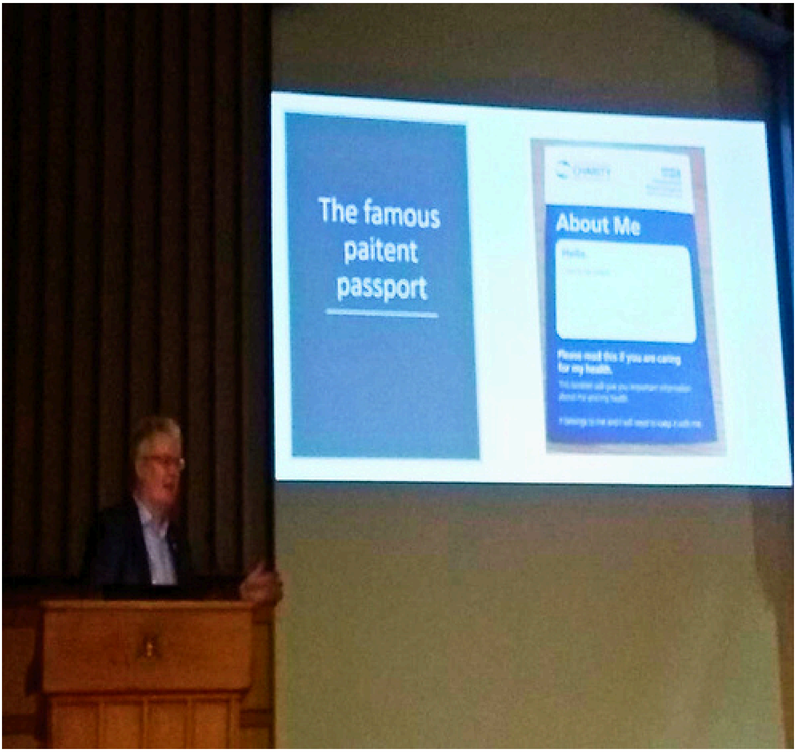
5th September 2018, Simon Cramp describes his work with Chesterfield Royal Hospital to develop and launch a booklet, so that patients who find communicating with clinical staff difficult have all their information in one place, making hospital appointments and admissions easier for patients and staff.

My twin brother and I were born three weeks early, weighing less than two bags of sugar and to begin with we didn’t breathe. We were born in August 1971 in a theatre, not an operating theatre, but a lecture theatre - so that the student nurses and doctors could observe a multiple birth. My brother died just over three years ago; and I was born with a learning disability, long term heart problems, diabetes, arthritis, dyslexia and dyspraxia, so I sometimes get my words in a muddle, and I am very clumsy. I take lots of different tablets, but I am just grateful to be alive and living in my own home. About 18 months ago I had to go into hospital to have a procedure checking how my heart was doing. It meant I needed to stay in hospital overnight. I found out that when people go into hospital as an emergency, or for something which is planned like mine, they can’t use the medicines they would usually take at home because a hospital doctor needs to give you another prescription. This meant that I didn’t get my normal tablets until midnight. I was also given a bed on a ward where someone was talking all the time which meant I couldn’t get to sleep easily. I thought this wasn’t very good for people with a learning disability, as sometimes we find it hard to communicate with clinical staff or have things we need to talk about which are sensitive or difficult. So, I talked to the patient and liaison service (PALS) about how we could make things better. I suggested we developed a patient passport or, as the hospital has called it, the ‘About me’ booklet. The passport asks about things like what people think they are taking medication for, do they need glasses, how they normally behave -it’s all about helping people with autism, a learning disability, mental health or sensory problems. The book stays with the patient and can be added to the red bag scheme for those people who are being admitted to hospital in an emergency.

Vikki Develin, the Trust’s Patient Experience Manager, explained: “The booklet highlights straight away whether a patient has any communication difficulties. It will allow our clinicians to see, at a glance, some of the vital information that they would possibly have difficulty obtaining, as well as helping them to quickly understand how they can best communicate with the person they are seeing”.

I am really grateful to the staff from the hospital for taking my idea on board and working together to develop it. The ‘About Me’ books can be picked up from PALS in the hospital’s main entrance and will also be handed out to patients on the wards and in outpatient clinics. I hope that having the booklet will help make people’s experience of hospital better and will be a helpful tool for the Trust to improve patient care. For more information about the scheme visit the Chesterfield Royal Hospital NHS Trust Foundation website.

In September 2019, I produced the previous Blog and spoke at a national NHS England Conference.



Covid 19

A personal view: I doubt if I’ll get a gong for speaking my mind, but I can't change who I am. Well, I have hated the lockdown and the pandemic and the issues surrounding the disease which are still with us. I feel the government has not treated those on legacy benefits very fairly, and the banks' so-called help for those of us on low incomes or poor credit didn't provide much assistance. When the government uplift, that they do every year to help with inflation was last £20 a month, it doesn't come near to those new claims on Universal Credit who, according to government ministers, can get up to £1000 more because of COVID-19, unemployment, furlough, and other schemes. The government has yet again provided food parcels to those that need it, but the system was rubbish and shows that the government really didn't care about those who struggle to support themselves. The government's sole concern was getting the economy going and those who can survive. It's a disgrace, and I am angry that minister after minister and official who imposed the strictest lockdown rules since the 1920s, thought that the rules didn't affect them.

When the prime minister talks about "we are in this together," he talks, as we all know, nonsense. That's how angry it makes me feel. I had to shield because I was one of those clinically vulnerable with heart problems and type 2 diabetes, and I feel pretty angry and stressed about this. Those who were shielding have been left abandoned by the government's lack of thought. Disabled people have come off worst. Those not on Universal Credit - I'll let you decide what I am on, and it's not UC - the so-called £13 increase is pathetic. Banks have made it hard; everyone has put their prices up by 50 per cent, and I have struggled and am still struggling.

Banks being lazy when they say send communications by post, and you can't get to the branch, they send you text messages. I am very wary of messages from high street banks and other hotels as people phone me out of the blue, and I nearly got conned into giving my bank details. No, I can smell a lie, thanks to my work with Ofcom. As I mentioned in the first book, while we gave advice, I also learned to do my on-the-job training. I do reviews for books and learn after I read the book to help understand what it means in law or good practice. I read up on my rights, and in the past, used the political system to help me understand the law, i.e. Consumer Rights Act 2015 Section 75, Equality Act 2010, Data Protection Act of 1998 and 2018, and GDPR regulations. These are my bibles. When people follow bad practice, I will not put up with it for my fellow friends and others with learning disabilities. Please don't think I speak for them, as I can't. It's very difficult to speak for the 1.5 million in England.

One person thinks they can, but as Toby Williamson says, I try and see the bigger picture and join the dots as it were. But during COVID-19, the government was the worst in living memory - even worse than Thatcher in the eighties and early nineties, and that says something. They have a system called Universal Credit, but those who are on legacy benefits lose an average of £600. The design is great, but the delivery has been shocking. Implementation has been poor, and the disabled, as usual, suffer.

An interview with...Simon Cramp

Interview by Annie Tidbury - Learning Disability England.

An interview with...

Simon Cramp

Interview by Annie Tidbury, Learning Disability England

How did you become a Self-advocate?

I just decided at seventeen that I want to make a difference.

If you could change one thing that would make life better for people with learning disabilities, what would it be?

Make sure the government produce an easy read version of policy papers at the same time as the more complicated one. I got the first easy read version in 2009 produced by Photosymbols. I am so proud others got easy read or plain English versions to Valuing

People and other documents in the early noughties.

What needs to happen for people with learning disabilities to have good homes?
It's very simple. A good support system and the HOLD system. I was chuffed when I got my new flat some months ago. Although I rent it, it is brilliant as it is my own space. No-one can tell me what to do as I can simply show them the door. Some people need help and that is the beauty of the personal budget, you can use that for help to get washed and dressed and to do everything you need in your home. Sometimes people need help through tough times like my Dad did when my twin brother died in August 2015.

Why do you think it's important for people with learning disabilities, families and organisations to work together?
I think the best example I could give was #I'mWithSam. It was an event lead by Dimensions on stopping hate crime. Learning Disability England was part of it. It was launched at the House of Commons.

I went and I was supported by the Alicia Wood from LDE. I talked about my experiences.

What do you think is the biggest challenge for LDE?

Helping people and groups within the family to grow and be supported. Everyone's voice and support and encouragement will be the success of LDE and if that doesn’t happen it will also be the failure of LDE.

What are your hopes for LDE?

It's too early to say. The first policy conference will be interesting. On the eve of a new prime minister only a couple of months in the job, a new money man at the money department, the treasury and the calls from everywhere on the following day for government to realise you can't dress up social care and housing and health in fancy language as the fact remains that there are not enough services and not enough money for everyone to get the care they need. *Simon Cramp is one of LDE's first Lifetime members.*

Dan Goodley Podcast

Professor Dan Goodley invited Simon to be the first guest on his Podcast – ‘The Art of Medicine, Love, and Humanity. ‘

Here’s the introduction – ‘Simon has been a leading force in many campaigns to ensure that people with disabilities are treated as full human beings -with rights and the full capacity to play a meaningful part in all aspects of community life. As a person with learning disabilities himself, he has firsthand experience of the healthcare system and was written about this campaign and life in his book, the brilliantly titled ‘Don’t Cramp My Style’. We ask Simon to consider the idea of humanising healthcare, which he reminds us has to be considered in relation to the values that society attaches to people with learning disabilities.’

You can find the full podcast on Spotify.

A Campaigning Life - A public lecture by Simon Cramp – 14th March 2019

Hosted by iHuman, The Critical Psychology and Education Research Cluster in The School of Education, University of Sheffield.

Simon Cramp delivered his public lecture in Firth Hall on 14th March, 2019.

Simon talked about his campaigning life documented in his recently published book ‘Don’t Cramp My Style’. Simon is a Fellow of the Centre for Welfare Reform and a member of the Citizen Network. He works hard to try and promote the rights of disabled people at every opportunity. Simon has a learning difficulty himself, and he works with people with learning disabilities, to get the right support and information.

Simon offered expert advice on a wide range of issues to do with learning disability, based on his extensive experience working as a consultant throughout the learning disability sector. Simon's talk revealed his keen interest in politics and political structures, and his hope to make things better. Simon described his work over many years as a disability activist and has recently worked with Chesterfield Royal Hospital to develop a patient passport.

Anne Lawton, a student on The School of Education's MSc Psychology Conversion programme said: "Simon is a rare person. His example gives me the courage to carry on with my studies.

Reflections

David Brindle, James Hedges, Jon Rouse, Chris Day, Kate Eleanor Young, Richard Kramer, Andrew Cozens, David Wolverson, Steve Hardy, Lucy Series, Rebecca Lawthom, Professor Dan Goodley, Katherine Runswick-Cole, Beth Spencer.

David Brindle

Like many of Simon’s friends, I was worried to hear that he had been taken ill in autumn 2024 and had ended up in hospital. But I was unsurprised to learn that illness had caught up with him while attending a conference.

Happily, the NHS did its stuff and got Simon back on his feet within a few days – though, as you’d expect, he had one or two observations to make about the quality of his care. But, he admitted afterwards that he might need to take things a bit more steadily in future and would be thinking twice about travelling to events quite so often.

Well, I’ll believe it when I see it. Simon has been a fixture of many health and care conferences and seminars over the years, articulating the interests of people who draw on support since long before their inclusion became expected of event organisers.

When I have been chairing Q&As, I have often been grateful to see his hand raised, typically from the front row, especially when no one else has been willing to break the ice. His credentials? Sometimes, particularly more recently, an invitation as a person with lived experience - but in the past, invariably a press pass for a disability journal.

Simon was representing one such journal when he kindly invited me to accompany him to the “relaxed” Prom at the Albert Hall in London in summer 2024. We had arranged to meet at the venue in good time for the late-morning performance. I hope he won’t mind me repeating this story, but Simon was sent on a wild goose chase when he arrived alone at St Pancras station from his Chesterfield home, which he had left at the crack of dawn. First, Transport for London (TfL) staff wrongly sent him to the Royal Albert station in Docklands, 12 miles in the opposite direction. Then, when he texted me to say where he was heading and I told him to turn round, he was misdirected by other staff all the way round the painfully slow Circle tube line. Hot, thirsty, dishevelled, and carrying his usual assortment of heavy bags containing copious reference materials for me to see and for further appointments in London, Simon eventually rocked up at the Albert Hall just as the concert was starting. It's a good 15-minute walk from the nearest tube station.

I'd have been livid to have been given such poor advice, twice, by TfL staff. But Simon was remarkably accepting and thankfully, thoroughly enjoyed the Prom (which was indeed great). Later, he was able to recharge his batteries with a good pub lunch and was then busily on his way again to see other contacts, before heading back up to Chesterfield later that evening.

In light of his subsequent illness, Simon can obviously well do without such stressful experiences. His acceptance that these things happen, and the way he took it all in his tired stride, spoke volumes to me.

The thought occurs, and lingers, that people with disabilities and support needs face challenges in their daily lives that go well beyond the most obvious barriers. The more active they wish to be, the more frustrating those barriers must feel. Our public services have still a long way to go.

David Brindle is former public services editor of The Guardian

A thorn in their side!

James Hedges

I've known Simon for several years now. As a Press Officer for the Care Quality Commission (CQC), I first encountered him as a disembodied voice at the other end of the press office phone line, asking for details about inspections or policy positions. I became his contact at the CQC. Although Simon is an accredited journalist, he was not on the staff of a large national paper or broadcaster, and therefore, a busy press office often deprioritizes requests from someone like him. However, I always thought they underestimated the importance of having someone writing, blogging, and talking about care from a truly lived perspective, which is at least as important as mainstream news outlets. I have now moved on from the world of the press office, and I am grateful to be able to call Simon a friend.

I was diagnosed with dyslexia, dyspraxia, dyscalculia, and an issue with my short-term memory. Dyslexia affects people in different ways. Each diagnosis is unique, it can vary from the very mild, to issues with reading or writing. Mine own has always been on the more severe side. I have struggled to read, write, comprehend words, my brain will not see words or things or add them in where they should be. I can often get quite muddled; I have an extremely poor short-term memory and am unable to hold numbers in my head for more than a moment. I also have an acute tendency to fall over, knock things over, walk into almost anything and keep myself coordinated. When I was about ten years old, I was diagnosed and fully statemented with these conditions, which I wouldn't wish on anyone. The struggle to get a good education, to pass exams, and to build a career—especially in press and PR, where I worked for over 20 years—has always been hard and often depressing. I have faced many instances of discrimination and outright bullying due to my disabilities. It's an unforgiving profession if you’re different. Often, I've had to hide the fact that I am disabled to get ahead, preferring to be thought of as careless in my work or even stupid rather than face the career-ending stigma of people discovering my disabilities. Therefore, I have always admired the way Simon has never stopped being his true self, never stopped fighting for equality in the eyes of others or in the law. He has never stopped pushing back against perceptions of his disabilities or disability in general. His ambition, tenacity, and pure force of nature are extraordinary and an example I wish I had the ability to emulate. Often, engagement with people with lived experience can be tokenistic or paternalistic, but Simon has always pushed for genuine engagement and adjustment. If we are ever to reach a point of true equality for those of us with disabilities, we fundamentally need more people like Simon fighting for us to ensure the world we live in is a truly level playing field, where, following his example and in his wake, we can all reach our true potential and live not in the margins, but at the centre.

Jon Rouse

I met Simon through my work as a Director-General at the Department of Health from 2013 to 2016. My portfolio included national policy on learning disabilities, working for the then Minister of State, Norman Lamb. At the time, we put great store on ensuring our policy work was co-produced with people with lived experience and because of that, I got to know some amazing people, one of whom was Simon. I have to be honest and say that Simon was the first person with learning disabilities I had ever met who was an accredited journalist, and a very good one at that. Of course, Simon is much more than that, he is an advocate, a campaigner, a writer and a trusted consultee. What Simon doesn't know about Disability Rights probably isn't worth knowing about.

Simon is also a born innovator; when he sees an issue, her addresses it directly, for example in his work to ensure that people with learning disabilities are treated with respect and dignity when they have to go into hospital. Indeed, it was this work that brought Simon and I back together when I was overseeing the NHS in Greater Manchester from 2016-20.

One of the great things about working with Simon is that he is so empathetic. While he is tireless in pressing for positive change, he always recognises that senior leaders are having to juggle many different responsibilities and is always willing to negotiate expectations. While he will tell things as they are, fearlessly, he is also pragmatic in knowing that sometimes, positive changes are hard won.

Since leaving Greater Manchester, I have stayed in touch with Simon for one simple reason. I really like him as a person. Over the years, through our conversations, we have got to know each other as people and all the other issues we are grappling with in our lives. That context has strengthened our relationship and so, after a decade of professional engagement, I am also very pleased these days to also call Simon my friend.

Jon Rouse CBE

CEO Stoke-on-Trent City Council

Chris Day

The Care Quality Commission

Simon is a campaigner and a warrior for the rights of people who use services across healthcare. Like all those that speak truth to power, he is resourceful and persistent in the pursuit of change and improvement.

From my Special friend Kate Eleanor Young

“It’s so tough right now, isn’t it? Especially when the world seems to be all about bad news and we’ve got to keep away from the things we enjoy doing. It will get better though, and you’ve survived tougher times. That’s what makes you one of the special people I met - everything that happens in your life, you take it, and help others to feel better from what you’ve learned. Before you know it, you’ll be telling others about how you survived lockdown”

Richard Kramer

f*ormer CEO of Sense*

‘I have known Simon Cramp for 24 years in my capacity as Head of Campaigns at Mencap, Director of Policy at Turning Point and DeputyCEO and CEO at Sense. That is a considerable time to get to know Simon and his strengths and passions. I have seen him as a member of a Board, as a campaigner for change, and known him as an friend over that whole period.

Simon is very experienced in understanding policy development and campaigns and has a real passion for improving rights and services for disabled people. He has a strong interest in politics and is keen to effect change and is always up to date with the latest policy developments across a huge variety of areas of interest to him, particularly around disability policy and health and social care. Simon believes that campaigning must be evidence based, and he researches policy positions in an in-depth manner in order to make the case. He can recall past Acts and clauses of legislation and even which civils servants and politicians are responsible for the policy itself! That means what he talks about is data driven and intelligence led. He shares the same values base as his former and local MP, one Tony Benn!

Simon believes that to win the fight for better rights for disabled people, that we must be representative of the people we are here to help and those who support our movement forchange. He is not nervous about expressing his views and getting his points across to others, and does so in an authentic and determined manner. If he sees injustice, he will try and address it and effect change, persuading others to a different view. He has often persuaded me to take another look at issues or approach campaigning from a different angle or approach.

He believes that to be successful it is important to hear the voices and be representative of the people we are here to help and those who support a movement for change. He is used to operate on a range of levels and different groups of people, whether that is Chief Executives, Board members, Policy makers, or campaigners. Simon always has something to say about his areas of expertise and is listened to. He also corrects people if he feels that they are not answering the question properly or are trying to dodge the original question in the first place.’

Andrew Cozens

I have been fortunate to work in social care for almost 45 years and had the privilege of observing it from many perspectives from community development, front line social work, director, policy shaper, to board member of national charities.

For over 15 of those years, I have shared the journey with Simon Cramp, and we have surfed the waves of optimism and depression in the continuing search for a properly funded, rights-based approach that truly leaves its Poor Law origins behind. We are on the downward slope again, sadly, as the costs of energy and a weak economy threaten progress, just as they did after the Seebohm reforms in the 1970s.

Our last prime minister, but three at the time of writing, Boris Johnson, claimed to have fixed social care with his proposals to cap the costs of care for older people. This was never going to be enough, as it denied the reality of the requirements of all adults seeking care and support. Even this gesture has now been postponed.

Part of the problem is that for many people, politicians included, social care, unlike health care, is about other people and not themselves or their families.

Throughout my career in social care, I have always tried to hang on to the principle that all of us need care and support. It is the capacity to organise it ourselves that can be impaired by circumstances, life events or crises.

The trouble is that many of us working in social care have become used to separating the professional from the personal, and not anticipating our own current or future need for support from others.

Similarly, we do not routinely think about how we can best be supported or express preferences about how people relate to us. Ironically, this gap applies equally to those who
cannot communicate verbally because of illness or disability and to the most confident of communicators.

A few years ago, I was asked by SCIE to help showcase Helen Sanderson's work on one-page profiles. It shaped a conversation about my own needs, preferences, and personal outcomes in a way that was quick, direct but surprisingly thorough.

Based on that, someone supporting me in any context would know a lot about how I like to organise myself and how best to relate to me.

Even going through the process, I could readily see how it would work in all sorts of health and care settings.

I have always worried that assessment was dry, impersonal, and functional. One-page profiles can bring it to life, so the person shines through.

We should even go further and think about how we profile the characteristics of our streets, neighbourhoods, and communities to promote independence and mutuality. We got a hint of this during the pandemic when we focused on our collective duty to look after those whose quality of life was most impaired by the risks from the virus.

There does seem to be little appetite for our political leader to address the issues underlying social care. This follows a pattern of piecemeal actions over my lifetime in the sector. Margaret Thatcher's legacy was the growth of a care marketplace, generated by her unwillingness to invest additional resources directly to council run services. The Blair government encouraged direct payments, personalisation, and efficiency. Gordon Brown flirted with a National Care service, to parallel the NHS. The coalition government raised our hopes with the Dilnot Review and the Care Act; both never fully implemented.

Latterly, social care reform has been proposed to address its impact on two associated issues, disproportionately focused on older people. The first was the unfairness of their having to sell their houses to fund their own care. The second was, and is, the pressures social care market failure has on hospitals discharges.

Two recurring themes float back and forth in policy consideration, the need for a more funding, and pushing further and faster with the integration of health and social care.

Disturbingly, the political debate lacks any meaningful engagement with people using services, or those currently unable to access them. Simon and I agree that putting this right and listening to those developing alternative visions based around coproduction and rights is central to the fundamental reorientation needed.

We need to raise our horizons from fixing a flawed system, to developing a wider conversation about each other's assets and how they can help us all get by together.

David Wolverson

What an ambitious guy, Simon is! In a recent catch up, Simon tells me he is doing a follow up to his first book “Don’t Cramp my style” and he wants another reflection from me! No pressure!

I have known Simon from around the turn of the century. He has been a board member of Dimensions when I was the Chief Executive (he was my boss) and subsequently he became an employee (I was his boss!). Over the years, he’s been involved with a number of organisations, not least Ofcom and chaired sessions at various conferences. So, over these years, we have chatted about his roles and how he makes a difference in his engagement with organisations.

How do I describe Simon? I decided it was in a song from 1997 by the Leeds group Chumbawumba…

“I get knocked down, but I get up again”. These 9 words describe in my view of Simon’s life with learning disabilities (and so many of the other 1.5 million people with learning disabilities in the UK) The battles in his early years to get appropriate education and support pale into insignificance when you reach adulthood and fall into the underfunded web called adult social care. Here you fight a system which is based on rationing resources rather than starting from what helps the person get a good life. So, it was for Simon and his twin brother, Adrian. After many years, getting their own tenancy and making a home together. And then, Adrian falls ill and in his early 40’s, sadly dies 8 years ago.

What a huge emotional blow for Simon, but as per the song he picks himself up and continues to champion the cause of people with learning disabilities through his network. And what a network he has! Politicians, civil servants, journalists, and academics. Never get into a “naming who you know or talk to” with Simon, you will lose hands down!

Eventually, Simon moves into a more manageable housing association flat in his local community but fairly quickly he falls foul of anti-social and discriminatory behaviour from a neighbour. So unsettling that he wants to move out, which is yet to happen. On top of this, Simon also gets diagnosed with a heart condition, but none of this personal turbulence stops his “work” of promoting the cause of people with learning disabilities.

Simon is such a resilient guy. I really hate when people talk about “the vulnerable”; It is a way of “othering” people of making them diminished recipients of our good works. In reality every one of us has a set of vulnerabilities and we all need people to help us at those times. What I learn from Simon’s life history is that Simon and others with disabilities are some of the toughest people around in dealing with life’s societal obstacles and pitfalls.

When I recently met Simon for a catch up in a local pub, the woman who was serving kept saying “sweet”, when I was ordering a drink.

I thought it was about the taste, but it turns out that it is an everyday term like the East Midlands “duck” or the Yorkshire “love”. I had never heard it in my many visits to Chesterfield over the years but what I do know, is that “Simon’s sweet”

Steve Hardy

I don't exactly know when I first met Simon, I think about 10 years ago. I think it was at a conference run by Pavilion Publishing or Learning Disability. But, what I do know, is what an extraordinary man, always fighting the corner for people with learning disabilities. I also follow Simon on Twitter, who is a very keen tweeter; always standing up for the rights of people whose rights are often taken away or ignored. His passion for people with learning disabilities is evident is regularly updated on his blog. Interesting and thought provoking articles about Matt Hancock, the Covid pandemic, family law and the so many atrocities as seen on Panorama and Dispatches. Often telling the stories of people who are supposed to be in care and protected but suffer abuse from staff - I look forward to working with Simon again very soon.

Lucy Series

My name is Lucy Series. I am an academic, and my research is mainly on human rights and a law called the Mental Capacity Act 2005.

I first met Simon at a conference organised by the Housing and Support Alliance. I must have been doing my PhD, as I still had brown hair, so probably around 2010. Alicia Wood was showing me around, and stopped to introduce to me Simon. Simon asked what I did, and I told him I was researching the Mental Capacity Act 2005, and Simon said – casual as you like – oh yeah, I was involved in that, I helped to make sure they put in supported decision making and get the name changed from ‘Mental Incapacity Act’. As you can imagine, this left quite an impression on me. And, sure enough, years later I am researching the history of the Mental Capacity Act for a book, and there’s Simon, popping up all over the place in the historical record, sharing his views and wisdom.

Through the years we kept on bumping into each other at events. Another time he was speaking at a conference organised by the Essex Autonomy Project, at the Institute for Government. It must have been a few years into the Coalition government’s austerity drive by then, as Simon was speaking with passion about the devastating impact the cuts were having on disabled people. Something else he said then stuck with me. Someone talked about risk assessments, and Simon asked the audience (mainly academics and policy makers) “how many of you have to have a risk assessment just to leave your home, just to cross the road?” I hope his question stuck in their minds as well.

We kept in touch, emailing and tweeting and so on. Simon reviewed some books for my blog. We chat on Twitter. One day, towards the end of the pandemic, Simon noticed that the prestigious Socio-Legal Studies Association was having a conference, and asked me – shouldn’t we do something to tell people what has happened to disabled people during the pandemic? He had a point.

So, the conference agreed with our plan, and we put together a special panel of speakers from around the world. We delivered our panel remotely, because even towards the end of the pandemic, it wasn't safe for everyone to attend a physical gathering. Our panel included Dr Linda Steele from the University of Technology in Sydney, speaking about her extreme restrictions people experienced in care homes during the pandemic, Dr Emily Kakoullis, from Cardiff University, speaking about people who are clinically extremely vulnerable people to covid and the social model of disability, Professor Anna Lawson, speaking about reasonable adjustments (or lack of) for disabled people during the pandemic, and Simon. Simon spoke with passion about the brutal way that people with learning disabilities had been treated as disposable, reminding audiences about how some were told they could not access treatment, would not be resuscitated, if they caught the virus and became critically ill. He told us how it felt to be disabled and be told that your life was of less value. And somehow – and I think this tells you everything about Simon as a person and as a campaigner – he managed to deliver this harrowing message in a way that was moving, yet also kind, and funny. He was brilliant. I think this is the first time that a person with a learning disability has given a talk at the Socio-Legal Studies Association conference, and long may it continue.

So, here's to more campaigning with passion, humour, kindness and truth. Thanks, Simon, for seeking me out, calling us out, and keeping our focus where it should be.

Dr Lucy Series
Lecturer
School for Policy Studies
University of Bristol

An Alphabet of Simon

By Katherine Runswick-Cole Chair in Education, The University of Sheffield.

When Simon asked me to write about him for his new book, I wasn't quite sure where to begin, or what I could possibly say that would sum up all I know about him. In a conversation with our mutual friends Professor Rebecca Lawthom and Professor Dan Goodley, also at the University of Sheffield, Rebecca suggested using an alphabet to help with the writing and so here it is - an alphabet of Simon, which I hope captures some of the work he's done over the years.

A is for author, this is, after all, Simon's second book.

B is for brother, everyone who knows Simon knows how important, Adrian, his twin brother is to him.

C is for campaigns – Simon's first book is about his campaigning life

D is for determination, which Simon has needed to achieve his campaigning aims

E is for eloquent; Simon is an excellent public speaker.
F is for the friendships Simon has made along the way.
G is for good times, which Simon enjoys with friends and family.
H is for hope for the future and never giving up, even when things are tough.
I is for interesting, Simon knows so much interesting information.
J is for jobs, Simon has had various paid and unpaid jobs during his campaigning life.
K is for the kids Simon has inspired along the way, when they hear him talk.
L is for the legacy of Simon's campaigning life.
M is for motivation which Simon has and inspires in others.
N is for networks, Simon is the best networked person I know.
O is for opportunities, and for never missing a chance to improve things for disabled people.
P is for passports, Simon is a big advocate of patient passports in the NHS.

Q is for questions, which Simon is always ready to ask and answer.
R is for research, Simon enjoys learning about and taking part in research whenever he can.
S is for study, Simon enjoys study and always wants to do more.
T is for Twitter, Simon is a keen social media user.
U is for university, where Simon has been a guest lecturer and where he launched his first book.
V is for voluntary work, Simon has given hours of his time to campaigning.
W is for working together, Simon brings people together to get the job done.
X is for the e**X**traordinary life Simon has.
Y is for youthfulness, because despite a long time campaigning Simon still has amazing energy for the work.
Z is for zzzzzz because after all that I’m sure Simon needs a rest!

Beth Spencer

“A Rebel with a Cause" is the perfect title for Simon Cramp's second book. He is a tireless advocate and champion for people with learning disabilities, while remaining critical of the flaws in the system. He certainly deserves recognition for speaking his mind and always staying true to himself. Filled with firsthand experiences and testimonials from those who have worked with Mr. Cramp, this is an engaging and fascinating look at a life spent helping others. It would be inspirational for anyone wishing to make a positive difference in society. Keep fighting the good fight, Mr. Cramp.

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