



Hospital to Home:
Kasibba's story





Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

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Foreword

Kasibba is one of the most incredible people I've had the privilege of meeting in my lifetime. She represents so many of the things that I admire: she is smart, brave and determined, but more importantly she is bold and unapologetic in the way she chooses to express herself. She is a role model and someone that can teach us all about hope, resilience and self-belief.

I was first introduced to Kasibba in late November 2016 as part of a wider piece of work that Changing Our Lives had been commissioned to undertake for NHS England. This was part of the Government's Transforming Care programme, a national response to the scandal that unfolded at Winterbourne View Hospital. I remember being sat in a small, stuffy, clinical meeting room on a hospital site. This hospital was made up of a number of units for people with a learning disability and autistic people who were seen as 'too challenging' to live in the community and had been moved here from larger long-stay institutions some years earlier.

On meeting with lead clinicians, we (the Changing Our Lives team) introduced ourselves and explained the purpose for our business and the outcomes that would

be achieved from the Person Centred Planning work we would undertake for the following 12 months. These outcomes were simple: they were about people being supported to live 'ordinary' lives outside of the hospital.

We define an ordinary life as a life in which people are valued as people first, as loving family members, as rebellious teenagers, as paid employees, as community leaders, as homeowners and tenants, as neighbours, as friends and partners. An ordinary life is faced with its challenges and responsibilities. It's not about being kept away from 'potential risks' and being over protected. It's about taking risks, making mistakes, changing our minds and sometimes getting into trouble.

However, the mention of the word 'ordinary' seemed to highlight an underlying tension that we had felt on arrival. Then followed lines of confrontational questioning around the Changing Our Lives team's background, knowledge and qualifications, and explanations about the 'complexity' of the people that they worked with. We, of course, graciously responded to their questions and in turn questioned the clinicians about these 'complex' people they spoke of.

We were told about an individual who was described to us as an 'eye-gouger'. A woman with no family, kept in long-term segregation at that point for 20 years due to her 'dangerous and unpredictable behaviour'. There was a rhetoric to the narrative that surrounded her, attempting to instigate fear through mythology, which prompted me to ask what her ethnicity was. Sadly, I already knew what the response would be so the fire in my belly was already raging. It was at that precise moment I knew I had to fight for Kasibba. We all have a history that shapes us into the person that we are today and this history plays a part in forming our own identity. Enquiring about our history is a way that others grow to learn about who we are, but that requires them to show a genuine interest and curiosity about us as people. This in turn contributes to building trusted relationships with others. Kasibba's life in hospital was absent of that interest and curiosity.

After nearly 6 years of working with Kasibba as her independent rights based advocate, in 2022, aged 53, she was liberated from the power of others. The hospital site that she had lived on, hidden away from society for most of her life, was a thing of the past and a home of her own in the community awaited her and her new-found freedom. I never doubted Kasibba. I am incredibly proud of her and stand strong beside Kasibba and her many allies.

Lucy Dunstan, Deputy CEO
Changing Our Lives

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Call me by my name

It was once said that with the right team of people Kasibba could be a Queen.
Kasibba *is* and *has* always been a Queen.



Kasibba now lives in her own home with her own staff team and is happily creating her own version of an ordinary life. She has reclaimed control of her life and is finding happiness by choosing what she wants this to look like.

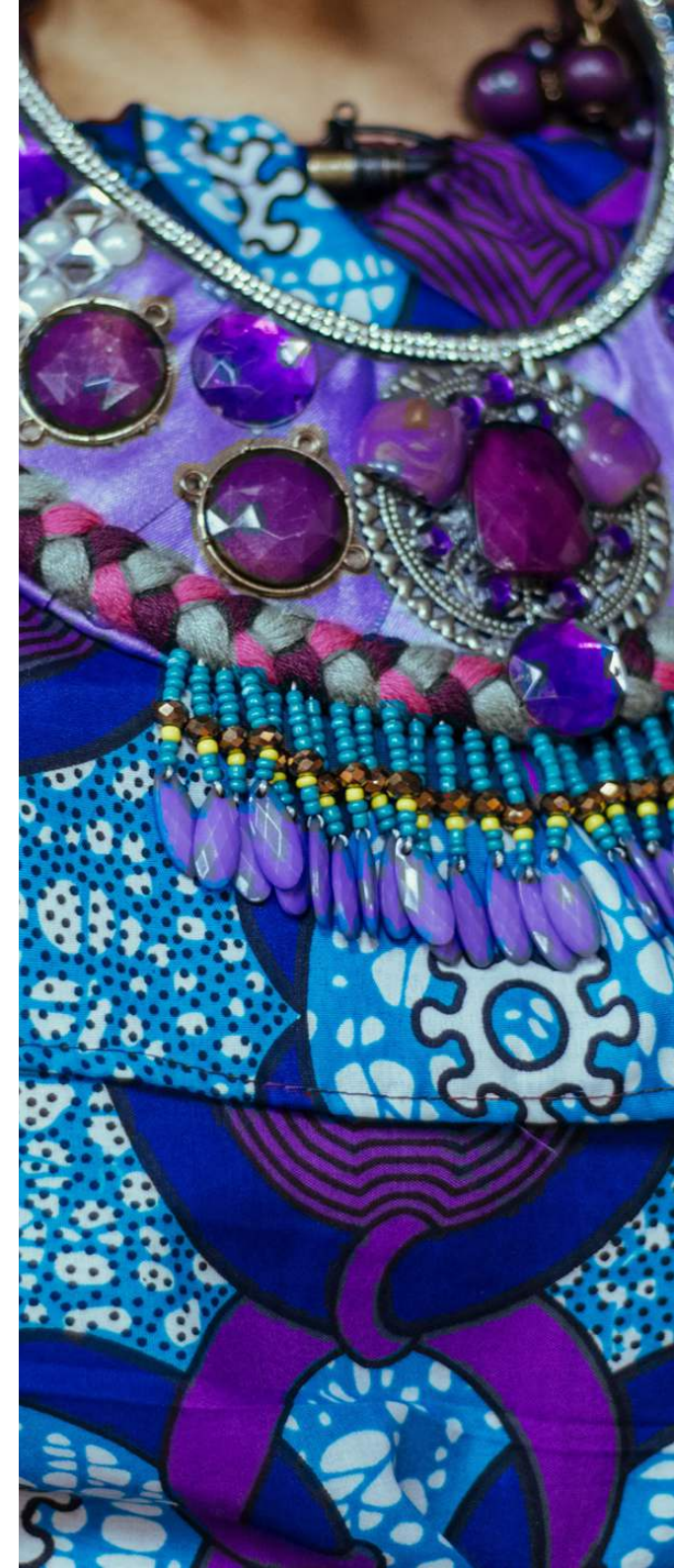
Kasibba has such a strong sense of identity and she has never lost sight of this, even when others did. In a book or film she would almost certainly play the protagonist, just as she does in her own life today. She is an independent and wise woman, with a sense of style.

'After her morning shower she sits on her bed, crosses her legs like a posh lady and picks out her clothes for the day.'

Staff member from Look Ahead

Her strengths include her adaptability, strong will and resourcefulness and how astutely she is tuned into the emotions of other people. She is what might be referred to as a 'fighter', as she has navigated her way through a difficult life alone. Kasibba is composed, possessing the ability to command a room and seize opportunities even among the most self-assured. She is a leader, not a follower!

Kasibba thrives in her own space, but is inquisitive and tactile and delights in the company of others, particularly those who exude confidence and offer an imaginative response to her sensory desires. She is curious and enjoys meeting new people and building relationships on her terms. Kasibba doesn't use words, but instead communicates using signs and gestures. She uses objects of reference to support her to understand what is happening in her environment and to make choices. Objects of reference are physical objects used to represent a person, activity or event. Over time the person learns that the object stands for that person, activity or event. Kasibba is very clear and consistent in the way that she communicates her thoughts and feelings. She knows what she wants and is flourishing by having control of her own life.





When I first met Kasibba she had no ownership of her life. She would spend between 23 and 24 hours of every day locked behind a door. Now she owns her home, owns her space and most importantly owns her own life. She lives in an ordinary house, on an ordinary street, just like anyone else. Kasibba is a sun-lover at heart and at her best outdoors in open spaces, feeling the warmth on her beautiful Black skin and giving her the time and freedom to relax or explore. She is incredibly youthful, fit and energetic and blessed with an athletic build which she maintains through her desire to be active.

'She had a great time. She was confident enough to explore the playground and the fields, running off from staff to explore.'

Team leader at Look Ahead



The hidden years

Kasibba was inappropriately detained in a mental health hospital all her adult life.

Kasibba is autistic and was placed in the care of Camden Council as a young child, most likely after being trafficked into the UK to work as a domestic 'servant', under what was officially described as a private fostering arrangement. However, the placement with her 'foster family' broke down and she was moved to a children's home. She was just 5 years old. Her adolescence marked the beginning of a lifetime of broken promises, trauma and fear.

Needless to say, people will let you down in life, but very few people are failed in the way that Kasibba was. I don't think it can ever be right to segregate someone as a form of care. It was clear to me that she expected very little from others and trusted more in her instincts and herself.

Autism was not understood in the 1970s. As a child of West African heritage, the statutory response to Kasibba and her sensory seeking '**behaviours**' came to be distorted by racist tropes of '**savage**', '**wild**', '**dangerous**' and '**violent**'. These words were littered through her hospital records.

Two years later, at the tender age of 7, Kasibba was moved to a large long-stay hospital. This was where she would reside—with the exception of a few months in her late twenties—for a period of 45 years.

25 of these years she spent locked away being demonised in long-term segregation.


Long-term segregation (or LTS as it is known in the industry) is defined in the Mental Health Act Code of Practice as a situation where **‘a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis’**. This is intended to **‘reduce a sustained risk of harm posed by the patient to others’**, which is supposedly **‘a constant feature of their presentation’**.¹

However, for Kasibba, long-term segregation was applied in such a way it was **inhumane** and **degrading**.

Despite having no mental health diagnosis, Kasibba was detained under Section 3 of the Mental Health Act between the ages of 18 to 21 years, before and after which she was an informal resident at the hospital. She was again placed under Section 3 of the Mental Health Act when she was 28 years old until she left the hospital aged 53.

In her early thirties, Kasibba was moved to a smaller unit on the same hospital site. This occurred when the long-stay hospital was closed in line with the government’s directive to dismantle such institutions across the country, a movement which was intended to be a step towards the de-institutionalisation of people with learning disabilities.

However, all that had changed was the buildings, with the loss of the usual long-stay hospital facilities (e.g. communal areas, swimming pool etc.) that Kasibba used to access. In reality, ‘hospital closure’ meant that her world just got smaller and smaller and Kasibba was re-institutionalised in a small unit on the same site, with much more restrictive practices and many more restrictions on her day to day life.



'We all remember our first visit to that environment—the shock of seeing someone who wasn't in prison via a window in a door. She was inquisitive and curious, peeping out her window from behind a locked door, all alone, with no family, no visitors, and no contact with the outside world, living in a sparse, self-contained area. The memory lasts forever.

It was worse than any previous visits to a long-stay hospital, with our minds questioning what we had just observed. This is the 21st century: it was hard to walk away, thinking about her, feeling overwhelmed, sad and helpless. I was glad of the long train journey home so I could try and process what I had witnessed.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

The solitary life that Kasibba had become accustomed to took its toll. As much as she showed great strength of character to survive such conditions, with the passing years, she regressed in so many areas of her life. She had to adapt to live in this restrictive environment as a direct response to the restrictions imposed upon her, which in turn had the effect of further institutionalising her. Over the many years that Kasibba spent in long-term segregation her world became so small that any quality of life she once had, diminished. She grew more susceptible to anguish and distress as she lost the tools she once had in her arsenal to communicate her needs and wishes, a basic human right and essential human need, eliminating her freedom of expression. What she needed was to be understood.

A new narrative formed. Not one of trauma or of an impoverished life absent of genuine human connection, fresh air, and activity, but around Kasibba's 'challenging' and 'complex' behaviour. This demonised her, portraying her as uncooperative, unpredictable and unable to adapt, preferring to be alone and locked in, being unable to communicate and only able to do things with staff that knew her well. Staff at the hospital believed that segregating her from the rest of society meant she was safe and, by extension, that they and others were safe, but she naturally became more vulnerable because of this narrative and the closed culture.

Kasibba had no control over her own life and was paralysed by the myths surrounding her and the restrictions placed upon her. It is these factors that established a vicious cycle, creating and reinforcing the rationale to keep her in long-term segregation for a quarter of a century.



'We all knew we had to get her out. The commitment to getting Kasibba discharged to her own home in the community grew and grew. It strengthened. The fire was there, ever present every step of the transition and legal process. Now the memory is deep-rooted but will never be forgotten.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

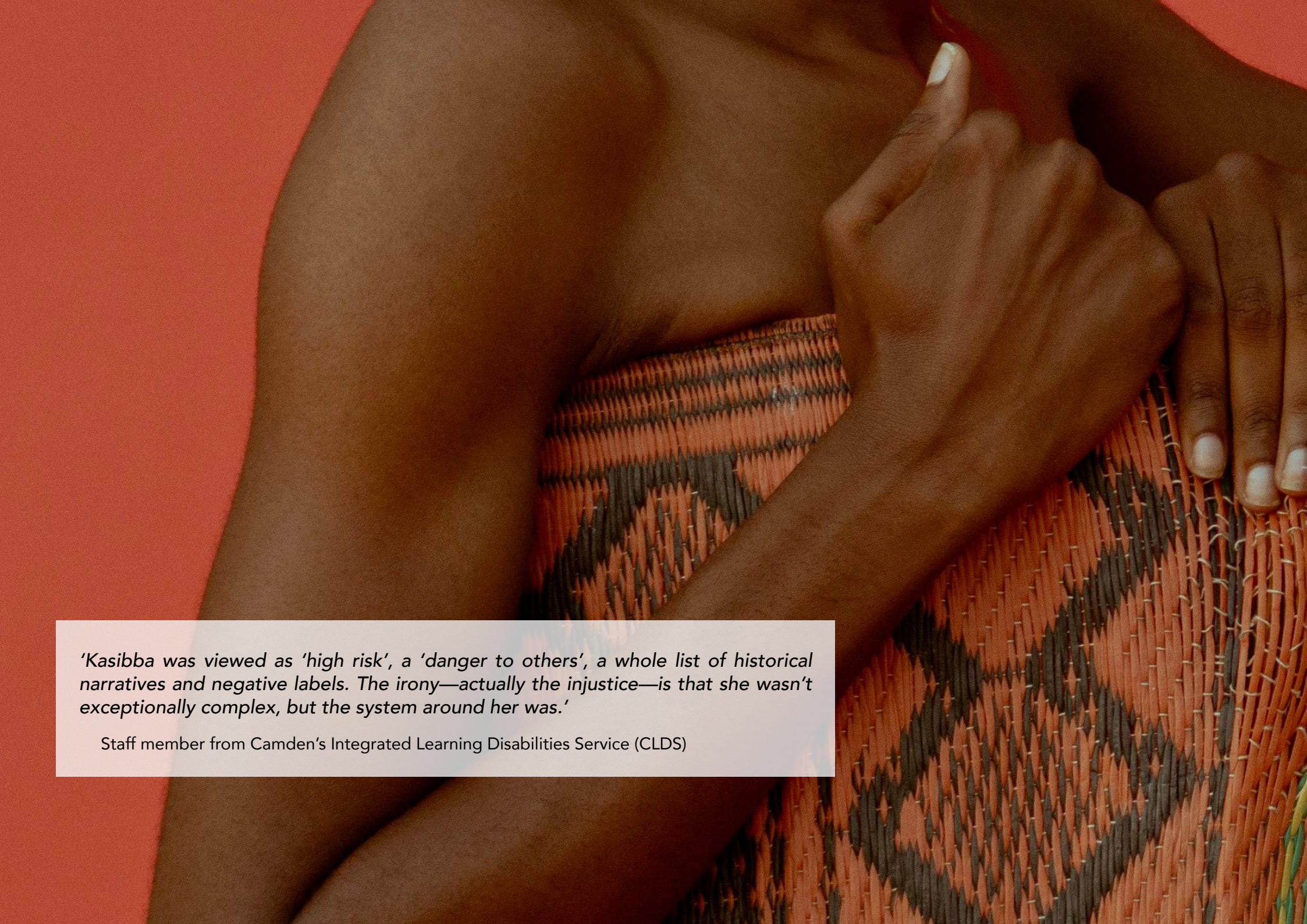
The team

The team around Kasibba consisted of a named social worker; an allocated NHS care co-ordinator (a clinical psychologist), who acted with active support from a nurse consultant; commissioners; and myself, acting as an independent rights based advocate, who was funded by CLDS. From the Court of Protection to the moment Kasibba moved into her own home, we fought tirelessly for Kasibba's voice to be heard and her rights to be upheld by demanding accountability, navigating and directing a complex system, and connecting the people that work within it.

This task was relentless: it took a holistic effort to overcome the systemic obstacles we tackled. The empathy our team felt, the drive we sustained, and the strength we asserted was immense. Irrespective of the challenges we faced, our values and drive to achieve ordinary life outcomes remained ignited, never straying from our end goal of giving life, freedom and dignity to Kasibba.

Working as a rights based advocate alongside people who are stripped of their most basic human rights is a challenging role. Sometimes people in this role will feel like they are a lone voice, fighting against the dehumanising labels placed upon the people they are advocating for by the systems and institutions that are supposed to be supporting them. Fortunately however, in the case of Kasibba's team, having a rights based advocate on side formed a vital element of CLDS' wider vision.

We worked as a team to oppose the status quo, calling out the racism we observed while working tirelessly to articulate and embed a narrative of hope and achievement to replace the mythos of danger and savagery that had built up around Kasibba. Where previous efforts to support Kasibba had been discouraged by the seemingly insurmountable barriers that surrounded her, we remained steadfast in our belief that such obstacles could be overcome, so long as we worked with tenacity, creativity and care.



'Kasibba was viewed as 'high risk', a 'danger to others', a whole list of historical narratives and negative labels. The irony—actually the injustice—is that she wasn't exceptionally complex, but the system around her was.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

The great escape

'Kasibba was not dissimilar to other autistic people we were already supporting in our area. We had to evidence repeatedly that we were of the view that she could live with a bespoke service in her own home in the community. We had already identified that a detailed two-year transition plan was required to support this move, well in advance of seeking legal authorisation to agree it.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

The six-year programme of work to move Kasibba into her own home required collaboration with the medical and clinical teams at the hospital. This work was underpinned by an assessment from Camden's clinical psychologist. For the first time, this put Kasibba's 'behaviours' in the context of her sensory and communication needs, which allowed the team to slowly change the narrative the hospital had built around her. It also detailed how the hospital had allowed Kasibba's quality of life to slowly reduce and the racist narrative to develop. These new insights enabled us to challenge both the court and the hospital to think beyond a medical model of support and to start visualising Kasibba's move into the community as the end goal.

Some years previously, the Court of Protection had intervened to prevent another person leaving the hospital. The Official Solicitor then suggested that this decision would return to put a stop to anyone else leaving the hospital, and for several years this advice was taken at face value. Moving Kasibba into the community was 'parked' as too difficult, and there was no active work to plan for her move.

The benefit of Kasibba having a named social worker and an NHS care co-ordinator working together gave the team time and space to fully consider the implications of the psychology assessment, namely that Kasibba was not a danger to herself or others. With a properly planned process, centred on her sensory and communication needs and diverting from the myth of risk, she could live an ordinary life in the community.

However, there remained significant barriers to overcome. In particular, the Official Solicitor did not accept this was in the best interest of Kasibba and resisted every effort to discuss or plan for such a move. The hospital consultant psychiatrist could not conceive the 'risks' associated with such a move, and the hospital staff continued to view and describe Kasibba in terms of racist tropes.

Changing Our Lives had developed a comprehensive Person Centred Plan (PCP) alongside Kasibba over many months, unravelling her identity and getting to the heart of who she is as an individual—beyond the labels and beneath her beautiful Black skin. This plan supported CLDS' contention that Kasibba did not need to be in hospital. However, the Official Solicitor disputed this.

This meant that the process to plan for Kasibba's move had to be managed at every stage through the Court of Protection. The court agreed the outline of a three-stage transition process, with a move between stages having to be agreed in court and supported by all parties, including the hospital. Recognising that both the judge and Official Solicitor were sceptical about this assertion, the CLDS decided to commission Changing Our Lives to continue to act as Kasibba's rights based advocate to ensure Kasibba's voice was heard by the judge and central to all proceedings that would follow.

'The CLDS works to a model we call the "3 Pillars of Autism": People, Places and Activities. This model asserts, that like the eponymous 3 legged stool, it is only safe to change one of the pillars at a time. This meant that the transition plan needed to ensure continuity of staffing (people) across the transition into the community. In light of this, the named social worker and care co-ordinator worked with the rights based advocate to undertake a mini-tender to find a specialist provider.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

This provider would not only need to support Kasibba in her own home in the community, but would also need to recruit new staff to provide in-reach support to Kasibba to start getting to know her and begin forming connections whilst she was in hospital. This in-reach work would be incremental and over a long period of time. After careful consideration by CLDS and Changing Our Lives, Look Ahead were selected as Kasibba's new support provider.

Meanwhile, the social worker and commissioners joined forces to identify and arrange the purchase of a house funded by NHSE. Changing Our Lives was central to this work also and agreed it was in Kasibba's best interests for her to purchase a car with her savings (her quality of life was so poor she had never had the opportunity to spend her 'personal allowance'). However, the involvement of the Official Solicitor meant Kasibba's savings were being drained for the 'privilege' of these legal costs, so a bid to NHSE was made to pay for the vehicle which was needed to facilitate the second stage of the transition plan: being able to visit her new home with her new staff team.

'Reading Kasibba's care plan against hearing what the nurses were saying and what I observed was conflicting as she was not as they described. It is so important we get to know the people we are caring for and not to base our learning on what we are told. I nearly gave up early on after hearing from the nursing team how dangerous she was and what she was supposed to have done. It put fear in me. Fear that wasn't there before. Soon I realised that something wasn't right. Naturally, I am resilient and I worked it out for myself. Having met her a few times I felt a lot of empathy. It was just a matter of learning to work with her.'

Staff member from Look Ahead

'We had our well-prepared checklist of what we knew she wanted and needed. It was three months into the first lockdown. Two of us in a car masked up, driving to meet estate agents, empty streets, parking on the side of the road after viewings to jot down our pros and cons as there were no cafes open to have a coffee. It was surreal! But we could not let the lockdown be a barrier to this planning phase, we had to keep it moving! We had Kasibba in our minds as we crossed each threshold, each room, the flow of the house, the garden, the ambience, the local community.... Jackpot! We found the right beautiful home to meet her needs and desires. This was finally happening..... SOLD! The world started to feel like a fairer place that day!'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)



Changing Our Lives' role was and is always to keep Kasibba front and centre of her own life by ensuring her wishes and feelings are pivotal to all decisions made on her behalf. This entails building a true picture of Kasibba's life and the events that had led to that point; curiosity around the depth of her culture and history; and understanding how she felt, who and what she loved, what she didn't care for and what made her tick. We brought our personalised and unwavering rights based approach to the plan and stood steadfast side by side with Kasibba every step of the way, challenging assumptions, poor practice, scarce evidence and injustice. Most importantly, we challenged those who were complicit in mythologising and demonising Kasibba's identity. There were many who were.

Changing Our Lives also played a key role in finding a new home and car for Kasibba, recruitment and training for the new staff team, and the countless meetings about her. We provided regular updates for the Official Solicitor at each stage of the process, including Kasibba's incredible progress; concerns relating to her wishes and feelings; and statements for Court of Protection proceedings. As the process advanced and another court statement was written it became apparent that Kasibba was striding ahead, just as she does quite literally when on the move! She was adapting quickly and defying the expectations and labels she was previously tarnished with.

'Kasibba is adapting to her new surroundings, as I was confident she would and I expect her to go onto flourish in her new home. What the wider multi-disciplinary team must continue to ensure is that they keep up with her. As Kasibba is appearing more and more comfortable with the changes she may wish to move at pace with the move into the property, given the positive response from her related to its introduction to her life. All parties are wholly encouraged by the strides she is making - she continues to set the pace and her new staff team are responsive to this. It's vital we are prepared to respond to her and her wishes as she is ready.'

An extract from a court report written by Changing Our Lives



The move

Kasibba's new team had been carefully preparing, getting her used to her new home for months. Initially just by driving past the house; then stopping in the driveway for a couple of seconds before driving off again. The first real milestone was Kasibba getting out the car. The team had agreed to just stay in the driveway and let her walk around, allowing her to explore at her pace. They thought that the house would probably be too big of a step. However, bold as they are, when they saw Kasibba had no issues walking in the driveway, they decided to open the front door. Much to their amazement she went into the house. Just the hallway, only briefly, but she stepped into her house for the first time.

Curious as Kasibba is, she immediately tried the doors. Were they locked like in the hospital? What was behind them? A room with a bed. What was she thinking? Did she know this was her bed? The team were briefed to only open one room at a time, so as not to overwhelm her. But she had other plans. She made her message quite clear: 'I want another room open'. This she indicated by grabbing staff's hands and leading them to the door, putting their hand on the lock and insisting that they open them. Bedroom, explored. Living room, explored. Bathroom, explored. What started as a few minutes per visit quickly grew into half an hour, an hour, an hour and a half.

By the time moving-in day came around, Kasibba was quite familiar with the routine: drive to her house, go into the house, sit in the living room with a snack and a drink. In the days before she moved, she had started asking staff to leave the living room and to let her be for a while, as if she knew it was hers. Her space, for her to enjoy and take ownership of. Moving-in day was no different: driving to her house, spending time in the living room with a snack and a drink.

Except this time, there was no driving back at the end of it.

'Before setting off from the hospital, we ensured that everything was as normal as possible. No emotional goodbyes from the staff, no delaying – just a normal drive on the face of things. This was vital, as anything out of the ordinary would likely cause confusion – though somehow I believe she already knew what was going on. She could sense it. We had told her, after all, multiple times – she was going to her new home. It was often said that Kasibba doesn't understand too much of what we are saying, though her current team don't believe much of this – she surprises us all every day.

We set off and followed our routine. Car. Driveway. Snack and drink in the lounge. An hour went by, and another... This would normally have been the time to go back. We were waiting for her to start asking to return to the hospital, to be driven back to what she had known as home for decades. We waited until dinner time – 5pm. Nothing. No requests to leave, no restlessness. Just Kasibba enjoying herself on her new sofa.

We decided to treat the day the same way she was: like she had always lived there. We gave her her medication, followed by her evening meal. She devoured her first home-cooked meal in her new home – a sign she is comfortable, as otherwise she refuses to eat. At this point the staff started to relax. We had imagined all sorts of scenarios in which Kasibba might have become unsettled, with the staff being unable to explain to her what was going on. We felt for her, though we knew that in the long run she would be much, much happier. But no such doom scenarios were necessary. Kasibba just strolled around her house as if she had always lived there.

That night, she put on her pyjamas and went to bed. Those who didn't know any different would have never guessed this was her first time living in the community. Kasibba was home.'

Team leader at Look Ahead

The new narrative

In the summer of 2022, after a six-year programme of work, involving thousands of hours, Kasibba finally left the hospital and moved into her own home in the community. Her ordinary life has been made a reality and she is now free and ready to live the life she so deserves.

'Kasibba is coming up to the first anniversary of living in her own home in the community, which is to be celebrated! Her first tenancy (security of tenure); her own car; her own dedicated team; Kasibba has done herself proud, we are in awe of her unbelievable resilience!'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

Kasibba is now queen of her own castle: she is in control, at peace with herself and her surroundings, and rich with the happiness that this brings. When she can, she spends her days as most sun-lovers do, in her back garden feeling the warmth of the sun on her skin and indulging in her own existence. Her life has changed extensively and she has mastered the monumental changes that were required to make this happen. She is supported by her staff team at Look Ahead who are warm, curious, compassionate, and solution-focused, committed only to ensuring that Kasibba is supported to live the ordinary life she chooses. The team are learning with and from Kasibba as they get to know each other and celebrate her power, womanhood and ongoing accomplishments.

It used to take Kasibba a long time to trust and get to know people, but this has changed. Relationships with her team are precious, honourable and reciprocal in their nature and Kasibba often hugs the staff she likes the most. She is comfortable and able to connect with staff whenever she wants, where previously she would have to rattle the door handle, shout repetitively or kick the door to get attention for help or company. What is warming and fulfilling for Kasibba and those around her is the shared understanding and interest in her rich West African heritage and the care and consideration that staff show relating to her ethnicity.

'Kasibba loves to show her beautiful legs in her dresses. I have suggested that we try buying mini dresses from now on and see how she feels in them.'

Staff member from Look Ahead



When Kasibba first moved in, she would get quite anxious around unfamiliar people, just as she previously had been in the hospital, banging and kicking to get them away, pushing them out the door and scratching if she wasn't listened to. This has changed dramatically as she now sometimes chooses to greet new people, taking them by the hand and proudly showing them her home. Kasibba is quite happy to invite people in, to meet new people and get acquainted. She feels safe around her staff team; she knows she is safe and secure where she is.

'Staff call her "Aunty", "Aunty Kasibba" or "Aunty K". As we are African, we don't use first names. It's very much a cultural term that we use to show respect and endearment. The way she reacts is so positive, she loves it.'

Staff member from Look Ahead

Personal responsibility is a critical aspect of accountability and, most importantly, is also a right. Kasibba is further developing old skills that were re-introduced as part of the in-reach work in hospital. She will take her laundry to the washing machine, often doing so without prompting. She can strip her bed and take the bedding to the washing machine also. Often choosing to pick her own snacks, she is no longer being handed things that are chosen for her; she has the choice of what to eat and drink. She can independently open her kitchen cupboards and the fridge, whereas before she barely had access to a kitchen.

Kasibba spent her first few months in her new home looking through the kitchen window, getting familiar with what actually goes on in there – she may not have seen a kitchen in action in years. Nowadays, she will come in when she pleases to smell the aromas of the food being prepared (rather than just being handed the end product) and has started to help out by stirring the food and adding pizza toppings to her very own home-made pizza (no frozen stuff here!). She will also add ingredients to the bowls, pots and pans. Kasibba is certainly not missing the bland pre-packaged food that she was made to endure in hospital. Instead, she is indulging in the pleasure of flavoursome and spicy home-cooked foods, sometimes sharing fufu or other West and Central African staples with her staff team.

'It's the small things, but actually, they are monumental. It didn't take long for Kasibba to no longer want locks on her doors! When she first moved in, she was curiously watching the staff cook each day in her new kitchen. This brought it back to us all, how she had been denied the most basic day-to-day tasks that we all take for granted such as her food just appearing in the dining room.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)



Kasibba now indicates to staff when she wants to go out. The strict routine she once had is a thing of the past and the confusion and anxiety she once experienced relating to the structures imposed on her have fallen away. Nowadays, she just picks up her Crocs from the cupboard and her object of reference to indicate to staff she wants to go out. She does whatever she pleases, whenever she pleases. When something is offered at a time different than usual, no problem!

'If all else fails, she even has the freedom to take staff by the hand and go out the front door herself to walk to her car!'

Team leader at Look Ahead

Kasibba recently went to a local park and fields for a run (as her Person Centred Plan suggested she would!). No months of preparation, carefully driving past for weeks so that she could gain confidence – they just went. Kasibba had a blast. It just goes to show how much trust she has in her staff team. In the hospital she would refuse the drive if her car was parked in a different location – now they can take her to the park and she relaxes, enjoying a snack and a drink in the sun.

It feels only fitting to end Kasibba's story with the beginning of the rest of her life. Only weeks ago in the hot June weather Kasibba, 'the sun-lover' could be found in her beautiful garden assisting staff with the pruning of her climbing plants and keeping cool by having buckets and buckets of water poured over her as she revelled in running beneath them. She'll be hoping for a hot summer!

**The book
(never to be judged by the cover it's given)**

When we go into a person's life we should all be conscious of the privilege we have and that we are often one more in a long line of professionals who have come and gone.

With a focus on quality of life and ordinary life outcomes, the team around Kasibba have minimised the challenges that once plagued her. At all times, Kasibba has been clear about her wishes and feelings regarding these challenges: all she needed was to be heard. The listening ears have meant that the 'behaviours' she once exhibited have fallen away, as have the medications and overwhelming sense of risk around her. Remember, Kasibba is a leader: she's always been one step ahead. In coping with change and unfamiliarity, she encourages everyone around her to manage their own anxieties optimistically, to take positive risks and maybe get into some trouble! In the long term, this will give her staff team and others' the confidence to give things a go, so they can learn and grow together.

'We did everything they said we couldn't do and Kasibba did all the things they said she wouldn't.'

Staff member from Look Ahead

'In our theoretical learning regarding long-stay hospitals, Goffman talked about the "loss of self". Kasibba was 'othered' in all conversations with professionals and not seen as an individual with her own unique needs. Her personal past and history were lost, as was her identity, her Makaton signs and her skills. She was shrouded in negative labels and not perceived as an individual in her own right at all. She was repeatedly pathologised.

In essence, Goffman perceived "psychiatric hospitals as establishments that shared the same characteristics as prisons, concentration camps and monasteries" and argued that patients "were subjected to restriction of freedom, suffered from the stigma of being a psychiatric patient and had their normal social roles taken away".²

Kasibba's life took place behind a locked door 24 hours a day, 7 days a week, 365 days, 52 weeks a year. Every day for a 25-year period she spent alone, in segregation. The previous 20 or so years were within the long-stay hospital, in the same grounds, but a different building. That's above 45 years spent in hospital.'

Staff member from Camden's Integrated Learning Disabilities Service (CLDS)

But this is not just another story. This is *Kasibba's* story. It's not ours to own, nor ours to share, but learn from it we must. There are many lessons.

References

1. Department of Health (2015) *Mental Health Act 1983: Code of Practice*, p.308. London: The Stationery Office. [Online] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF.
2. Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, p.xxi. New York: Anchor Books.

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In order to protect her identity, we have not used Kasibba's real name.

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**No one is *too disabled*,
or *too affected* by
mental health difficulties,
to lead an *ordinary life***