



Kieran

“Kieran can get on with his life now... it really feels like we've taken massive steps with My Life.”

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Date: November 2020.

BACKGROUND

The weather was terrible, but Kieran was desperate to go out. With his My Life Support team leader and father, Grant, they began the slow walk up Winter Hill, the landmark on the West Pennine Moors which looks out over all of Greater Manchester.

The rain was lashing down, the mist so thick they could barely see in front of their faces. And then, just as they reached the top, the cloud suddenly cleared. Kieran could see for miles.

“It was such a great moment,” remembers Grant. “Not only a massive achievement, but a simple metaphor for the way his life has changed. Life was laid out before him, there were possibilities. A future.”

Kieran’s story is heartbreaking, but through perseverance and incredible cross-agency teamwork, a young man with autism who has been locked in secure units for over a decade is finally able to live in his own home, with support from My Life. It’s been a long, hard

road, but as Grant says, “Kieran can now get on with his life - as can our family.”

When he was a teenager, Kieran was admitted to hospital after a poor reaction to some psychotropic medication intended to stabilise some of his more agitated behaviours. Unfortunately, it had the opposite effect and his parents were encouraged to have Kieran sectioned while the medication was amended.

Devastatingly, a situation initially intended to be time-limited ended up with Kieran in various secure accommodation establishments for 12 years. Jeanette McDonagh, his responsible clinician at Mersey Care, believes that a lot of the behaviours that people became concerned about in that time were acquired from others at secure units. As his father Grant says, “he picked up a lot of bad habits and attitudes; it was almost like a prison mentality and if you showed weakness you were a target.”

Kieran would attempt to abscond from these places for no other reason than he wanted to see his parents. “All he ever asked was for us to get him home,” says Grant. But some of those episodes ended with police involvement, and even though there was never any evidence or formal accusation of wrongdoing to members of the public, Jeanette believes there was an attempt to demonise Kieran and resist any attempt to approach a discharge from secure accommodation.

In 2016, Kieran was transferred to Calderstones - now Mersey Care Whalley - and psychologist Ellie Hickman quickly established that a lot of his behaviours could be attributed to autism, which had never previously been diagnosed. “Ellie rang me asking for more information about Kieran,” remembers Grant, “because having observed him on the ward, she wasn’t entirely sure why he was in a secure unit at all.”

“None of his behaviour was matching what was in his notes,” he says. “Finally it felt like someone was listening to us and it was so refreshing; he was reassessed, as he should have been at the very start.”

Jeanette, the team at Mersey Care and other agencies could then begin the process of trying to discharge Kieran, after a period during which he began having overnight and weekend leave at home. However, as Andrew Jackson - from Greater Manchester’s Specialist Support team and part of Kieran’s discharge planning for over two years - notes, there were strong opinions from Kieran’s local authority that he should not be able to live in the community.

“No-one from local services had taken the time to get to know Kieran, to understand him, to be able to manage and mitigate Kieran in the community,” he remembers. “Every step there was a negative comment to stall or sabotage Kieran’s discharge.”

“I’ve been qualified for six years and come close to discharging 40 people,” adds Jeanette. “Kieran had enjoyed overnight leave at home 300 times without incidents - I knew he was nowhere near as risky as some of the people I have dealt with. But I was being advised the opposite.”

Nevertheless, after letters - some of a legal nature - had been passed between Mersey Care, the family, NHS England and the chief executive of the local council, Rachel Wigglesworth from the CHC team was able to progress a plan to discharge.

THE PLAN

The family's initial desire was simply to bring Kieran back home, and Grant had begun to look into setting up a limited company which could administer his personal health budget through a direct payment. However, a number of factors made that impossible, not least that Grant was more than aware that if his personal circumstances changed, Kieran would have to go back to hospital.

The family began to look into finding a house for Kieran where he could live independently while receiving the support he needs. Grant had expressed his belief to the NHS strategic planning team that for the annual amount it was costing various agencies to keep Kieran in a secure unit, they could probably buy a house. So after a lengthy bid process, a pot of money was accessed from NHS England Estates to do just that. It was then covenanted to Golden Lane, the housing arm of Mencap, on the condition that only Kieran could live in the house. Kieran could, once discharged, live there for the rest of his life, paying rent to the NHS via his benefits.

Nevertheless, there was still some resistance from the local council, and a suggestion was made that Kieran would be better going into a shared house with people his own age and support staff. Kieran was adamant that these were not his wishes; Grant remembers him saying "well if that's the case, I might as well stay in hospital."

But as Andrew Jackson says, "we were actually causing him harm by keeping him in hospital. He was vulnerable, he'd experienced a number of assaults. So it was getting the house that made this transition concrete - literally."

In early 2020, the family were referred to My Life Support, who have wide and expert experience of helping people live their best lives in their own homes. Clare Roberts, from My Life's Support Planning team, met Kieran and the family at the hospital and began to explore what a personalised package that worked for Kieran and his family might look like.

The most important part of the support plan was clearly that Kieran needed a consistent team around him (see The Team) who not only knew his needs but could combine a highly-skilled approach with adaptability, flexibility and friendliness. A rota which allowed for 2:1 support during the day and a waking night was worked on, with the parents having a role in the early period. A third party managed budget was agreed (see How Kieran's budget is managed) in principle.

My Life was also involved in many multi-agency meetings to discuss Kieran's transition. It was clear that although the historical files on Kieran contained a lot of inaccurate information, My Life's Safeguarding team would have to be involved, and Gareth Hughes from our team worked with the local police to pre-empt any potential issues before Kieran was discharged.

"Gareth has been brilliant," says Jeanette. "He's liaised with local police, he really got Kieran's situation and condition, and has been able to address any issues which have arisen."



THE TRANSITION AT MY LIFE STANDISH

It was clear that although Kieran needed to be moved out of secure accommodation, there would have to be a transition period where he slowly became accustomed to what a 'normal' life might look like. My Life were involved in what Kieran's clinical lead on his hospital ward, Carol Burton, calls a "creative transition where we got people around the table and worked out the best options."

As My Life had already discovered, the amount of historical paperwork surrounding Kieran would have put some providers off due to the perceived risks - even if it was out of date and largely inaccurate. My Life Chief Executive Caroline Tomlinson decided the only way to secure a successful transition was to meet Kieran for herself.

Everyone had noted that Kieran is at his best when he is being kept active outside, so he began to spend some days at My Life's site at Standish, an inspiring 84-acre facility where people can experience many activities overseen by specialist healthcare support staff including animal care, horticulture, horse-riding and much more.

"I spent weeks taking him out on the horse, teaching him, going on hacks around the fields and the community, and engaging with him on an ordinary level," says Caroline. "His staff team and sometimes his family came too, enabling us to all converse in an ordinary way.

"What I saw was a young man who had empathy for animals and people, a young man who needed a chance. My decision as the CEO was then simple to make, of course we could do this and while we all knew it wouldn't be easy, the most important work you will ever do will never be easy!"

"My Life at Standish was brilliant for Kieran," remembers Grant. "He'd been depressed, but going there cheered him up immensely. The staff from the hospital who came to visit him there said it was the most they'd heard him speak in five years; he wanted to do dog grooming and horse-riding where before he'd spend all day in bed. He also got valuable and safe interaction with people his own age, which was so good."

Kieran also had a chalet at Standish where he could have a base and meet the staff who would be working with him; My Life's Registered Manager Tracey Tolley remembers that he was initially very subdued and it was hard to get him to think about personal care. "Now, though, he's like a different person; I think because he felt looked after and looked out for".

"There were all sorts of therapeutic elements to his time at Standish, it had a massive impact on him," says Jeanette.

Kieran finally moved into his own home with support from My Life in the autumn of 2020.

THE TEAM

The family - and Kieran - were fully involved with whom My Life recruited to deliver the 2:1 support that he needs at home. Some staff members were provided by the family, and the parents themselves were employed by My Life too so that Kieran could transition into the home with people around who he knew and loved.

Over time, MLS will use its wide experience in recruitment to find the very best staff for Kieran's needs, matching people who have the competencies and confidence to deliver a high-quality service that is tailored to him.

This individualised approach means he should never receive generic care; Kieran will receive more senior staff as and when he needs them, with MLS and Alocura managing and allocating the budget for that process. All staff are rigorously checked and formally trained by MLS to ensure they provide the best-quality

care - and the training is ongoing to meet any changes in Kieran's circumstances.

Kieran also has a team leader who can act as a conduit between the family, My Life Support, Alocura and any funders or other agencies when quick decisions need to be made. Being able to advocate and negotiate on behalf of the family and Kieran so that their voice is heard in a partnership with the funder is fundamental to My Life's desire to get the best outcomes for people who need support.

Kieran's team are encouraged to be flexible and accommodating to his needs and wishes; the rota means his 2:1 support can include activities in the community. In the home, Kieran needs people around him that he can trust and that he knows - consistency of care is crucial. "You don't realise how much time you spend on care for someone; it's so good to have the back-up of My Life," says Grant.



HOW KIERAN'S BUDGET IS MANAGED BY ALOCURA

In collaboration with many different agencies and the family, My Life wrote Kieran's support plan, and the financial management of his third party managed budget is paid by Bury to Alocura outside of that support plan. This has many benefits, for the provider of care (My Life Support) but also Kieran. For example, if Kieran requires some additional support, Alocura has an up-to-date balance of his budget and can forecast the spend - meaning everyone is clear that the additional support can be costed and paid for.

Alocura also ensures the budget the commissioner is paying lasts Kieran a year, and continually liaise with My Life and the commissioner to ensure he is receiving consistent and continuous care. As part of this, Alocura receive a payment schedule from Bury, which in turn guarantees payment to the care provider on seven-to-ten day terms. This is crucial to Kieran and his family; they are assured that the outstanding care he receives from My Life Support is being paid for - and will be paid for.

Alocura also receive and manage the payroll for Kieran's staff, and work with My Life Support to ensure the presence of a fully-costed and highly skilled team manager; crucial in terms of liaising with Kieran, the provider and the funder to ensure consistent, long-term care.

Bury also receive monthly statements from Alocura and can ask for full, open and accessible audits at any time. These statements and audits would reveal that the costs to the commissioner of a package such as Kieran's, while significant, are far less than ongoing institutionalised hospitalised care.



THE OUTCOMES

The strength of feeling surrounding Kieran's new home and life is testament to the spectacular impact of Kieran's transition.

"I am absolutely over the moon for Kieran and his family," says Jeanette McDonagh. "This is his best chance and despite the difficult journey we've all managed to get the best thing for him at the end; a good care provider and a good house. I was actually quite emotional when he was discharged, because it's been such a battle. But he's presenting so differently; he's more relaxed, engaged, he's living a normal life now and hopefully we've got him out of the secure hospital situation for good."

Many of the transition team are still involved with Kieran's care, and Andrew Jackson has been delighted to have conversations about the future with Kieran. "He told me he wants to get married, which to me is a reflection of how he must be feeling being normalised within that house environment. He'd love a job; gardening or something, and we've been looking into that.

"Yes, there are still a lot of professionals visiting his home and he's bedding in. It can be overwhelming for him. But if there's any frustration from my point of view it's that we could have been doing this years ago; we've had a man living in an environment he should never have been in and now we're seeing the benefits of a complete care package that works for him."

Best of all, Grant says Kieran has gradually come back to his normal self and even though the family are part of his care team, their relationships have deepened. He is looking after himself a lot more, tidying up, running a bath, getting food out of the cupboard - Grant thinks that with the right support, he could fulfil a role in the community.

"He wants to do a tour of Europe - we keep saying to him one step at a time, but it's great that he has those aspirations. He can get on with his life now - his physical health has improved, his emotional wellbeing has got much better and he's able to choose how he wants his own home."

"You know, the thing he's still struggling with is that he has no limitations now. That's what comes of being locked away for 12 years I guess, but the small things, like choosing a film to watch together, have become massive for us."

As Jeanette says, "we're seeing progress on a weekly basis. He's sleeping better, he's engaging more. And for Kieran's parents, the impact on their wellbeing has been similarly massive. Honestly, this is the best transition we've done, and without the team working with My Life of the last 12 months, Kieran would never have been in this position."

What Kieran's Dad, Grant, says

"I have to say, my past experience of care and support for Kieran has made me incredibly cynical. Everything has been a battle and I've had to be stubborn. But with My Life, I quickly realised we'd found the right people. All the staff, from the chief executive to the chef in the cafe were so happy and caring, and that was obviously going to make a massive difference for Kieran.

It was a relief as soon as he came out. He can get on with his life now, and having him looked after in his own home so well by My Life has meant we can all have aspirations for the future. If I was doing all Kieran's care myself - what if I got hit by a bus? Our lives can't revolve around Kieran 24/7 - we've got four children and our own needs. So being able to gradually step back and have a parent-son relationship will be so important for everyone.

I want Kieran to develop because he feels safe, secure and relaxed, and it really feels like we've taken massive steps in the last few months with My Life and the other agencies to make that happen.

But you know the best thing? He's smiling a lot."



KIERAN'S FULFILMENT INDEX

My Life is committed to employing regular reviews and reporting to understand how the people and families we work with and for are using My Life, how they are feeling, where we can improve and where we are performing well.

This data is compiled independently and uses the well-regarded Personal Outcomes Evaluation Tool (POET) as a basis to understand a person's health and wellbeing, quality of life, choice and control and much more. From this we have been able to track the impact of My Life Support on Kieran and his family by comparing an assessment we made with him when we first began our relationship with our latest review in November 2020.

In Kieran's case we are absolutely delighted that there have been big increases in his physical health, emotional wellbeing and quality of life. We would of course expect a massive improvement in the home he lives in given he was discharged from hospital but it's also great to see he feels much more in control of how his days plan out.

We also repeat some of the POET exercises with the family to understand the impact of high-quality and consistent care on their wellbeing. It's wonderful to see that they now feel their relationship with Kieran has deepened, that their stress levels have markedly decreased and most of all that they are now far more able to concentrate on living their lives because he is receiving such high-quality care from My Life Support.

Exceptional increase: 60% or more

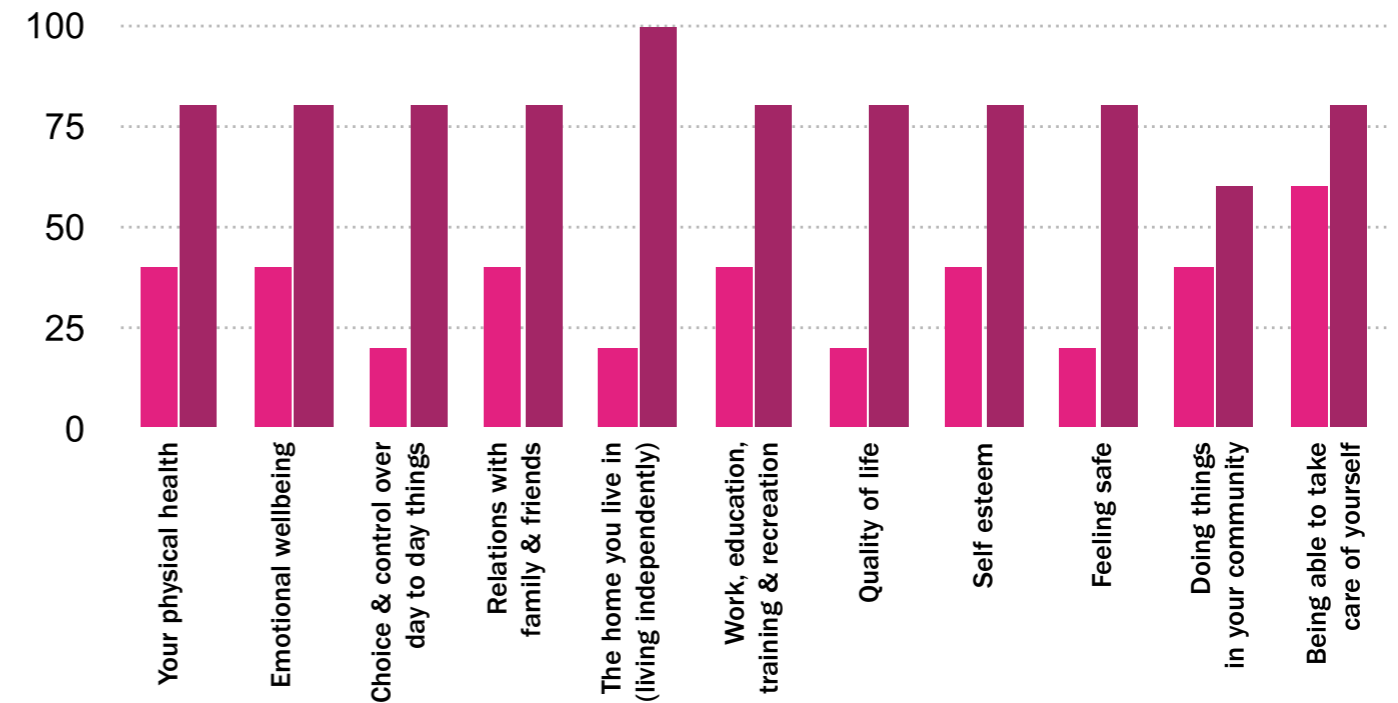
Good increase: 40-60%

Acceptable increase: 20-40%

Minimal: 0-20%

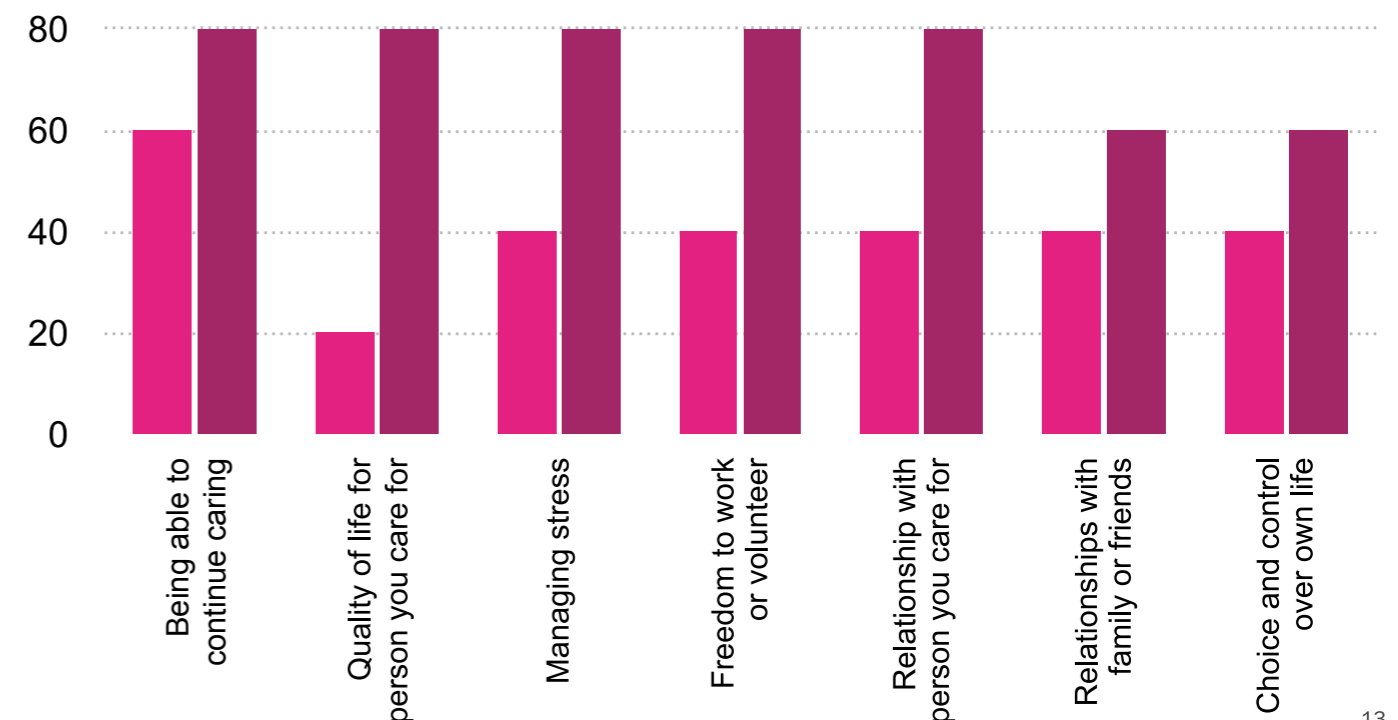
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