

Creating a place with Matthew

by Judith and Libby Ellis

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The story attempts to share with you how we have assisted our loved son and brother to create a place of his own. This has been carried out against a backdrop of having to undo other institutionalised forms of living. For Matthew, these were a medium-sized hostel for children and young people and then a number of group homes. The themes of this article are about how environments can disable (or enable) people, about the process of change for a family and about liberation.

We argue that the relationship between these things directly impact a person's identity. That is, we can disable people or we can enable them. This is relevant to those interested in the quality of human services and of policy that makes a difference for the very people it purports to be concerned about. In a blunt way – if you want to put money into real quality, then you must put it into environments and contexts which allow people to thrive and which enable and liberate people. So this is not just another nice case study!

The path into shadow

Matthew is 39 years old and known in many different ways. He is an Australian citizen, an uncle, a brother-in-law. He has a rich history and legacy from before his birth. The Mort family have a strong history in Australia. Some of the icons you may recognise are Bodalla Cheese, Mortdale and Mort's Dock in Sydney. He has excellent friendships with many individuals. He is a lover of nature and his enthusiasm for light, wind, water and trees serve as metaphors for what he is unable to speak. Being seen and responded to as a man with many roles, passions and interests has not always been, however, the dominant view.

His legacy and birthright were inconsequential in the face of the label of disability – a label his parents actively sought in the belief that it would help. They were also inconsequential in the face of the beliefs and assumptions of the powerful systems that were played out in his life once he gained these labels. The preoccupation to separate certain groups of people from our communities is deeply embedded

in our society and, so, its human service systems. It is this drive to separate people that really creates vulnerability. It is this which weakened his natural sources of power (when you are born this is your family) and so immediately undermined the very cornerstones of an inclusive life.

There are many past moments which have deeply influenced our actions to assist Matthew find his place and to crystallise our hopes for the future. The first glimpse is about human services.

Shadowlands

Very early in our life in England, kindly human service workers felt they were doing the right thing offering to take Matthew, initially into respite, and then for him to live in a kind of boarding school environment during the week. Like many other parents, the lure of human services was too strong to resist. Make no bones about it, we did need support. No-one offered anything else and certainly we knew of no other kinds of services. Eventually we grew dependent on them and co-opted into thinking that this was good – for Matthew and for us. Little did we know that these kindly beginnings were part of a process which served to reinforce the notion of Matthew as an 'outsider'.

Once in Australia, Matthew started at a school over 2 hours from his home. There were many other schools which were closer. They were never offered, and we did not question this. It was difficult to recognise it as a school. There were no children racing around, chatting to each other, playing, lining up for assembly. It was a school in which only adults held conversations.

Because of the distance from home to school, family financial circumstances and a family's own needs, Matthew moved from a young age to a hostel and then to a number of group homes. He began to live his life with a group of people whom he did not really know or with whom he had anything in common except his label of difference and disability. His co-residents were in the same predicament.

Matthew's younger brother, James, recalls that when

he visited the hostel, he did not know it at the time this was his first experience of Matthew's separation from us as a family. He didn't question it, he didn't know the politics of why Math might be there...he was only 6 – it was the done thing.

"While Libby and I got dropped off by Mum or Dad at school, we all waved goodbye to Matthew every Monday morning as he sped off with the taxi lady in the Humber. What happened after that I wasn't sure, just that I'd see Matthew again on Friday. Moving on a few years I started high school and Matthew wasn't there, Libby was. In hindsight, this was another disconnection enforced by unknown people. I did not understand it at the time. All I knew was that I would see Matthew from Friday to Monday, my weekend brother." (Matthew's younger brother)

So the separation also moved inside our family – we had become a part of the process – probably because it was the only process we knew. This pattern transferred to others outside our family. If others saw us voluntarily separating ourselves from Matthew, did this show them that what we were doing was the right thing?

Identity

Matthew eventually left the group home system when he was 25. Despite the fact that those working in the system were generally nice, his identity was only his 'disability' and we came to realise that his labels, severe intellectual disability and autism were more a function of what had been denied him rather than a true account of who Matthew was and that it was this and the environment that cumulatively disabled him.

It's very hard to describe this 'identity'. Imagine trying to explain your own identity. Some tangible examples include:

- Appearance – other people's clothes, clothes with name labels, bad haircuts, urine smell to clothes
- Constantly overweight.
- Overly dependent – unskilled, unmotivated, waiting on a prompt from others, as he experienced staff doing tasks day in and day out.



'taught' Matthew to identify with those he lived with and paid people rather than his family.

Reconciliation

And so this is Matthew's history with which we had to reconcile, say how sorry we were that it ever happened and that we were part of it. If Matthew was apart from us, then coming together must be the first step of change.

Reconciliation implies a coming together of parties torn apart. The rift of separation has not only created many painful experiences for Matthew, but we been fractured and broken by the experience. Separation of families sets up a split, a fracture that may take a lifetime to repair. It skews things in all of us. We ask you to consider the evidence around the impact of removal of indigenous children from their families (even where those families are considered 'dysfunctional').

In coming into new relationship with Matthew, we were forced to confront the past, understand our place in it, commit with each other to repair this damage, and then to build something new. In this view of reconciliation, we are required to bear the burden of our history, but also to know that the outcome of the actions we now take cannot be known in advance. We came together, perhaps broken and in pain, but we set out from there in the hope of ensuring that pain and wounds are not the only kinds of actions we will ever produce.

"I remember a change in our common thinking around the time Matt was leaving school. Mum had started to question what was actually going to happen for Matthew in the future. I believe it was a coming together of all the unjust things that had happened to Matthew over the years that had brought this questioning nature about" (Libby).

- Lacking communication skills – often the only people in the homes who spoke were staff. With high turnover rates, this was a nightmare for somebody needing to learn to communicate.
- Experiencing trust broken by those you were asked to place trust in.
- The learning of negative patterns of behaviour which remain with Matthew today.
- The environment

The light of change

When we decided to make change, it was liberating, almost intoxicating. We made a decision that, come what may, Matthew had to have a different life. It wasn't just that he had to move out of a group home. It was far bigger.

Matthew had to experience the things that make up a good life – love, being part of a family, having real opportunities, entering into relationship with non-disabled others, coming to grips with who he was and letting people know about this, being challenged, being known. He had to have a life where he could contribute, where he had voice.

At a very practical level he also had to have a different method of funding, a different service provider, and a group of people who were prepared to listen to his voice and act on it. This period lasted about 4 years. Drafting submissions in the small hours of the morning, phoning, attending meetings, talking to government personnel, negotiating, researching, writing reports and badgering. So, how was this different to the struggles of the past? All the time Matthew was living in a hostel and in a group home, at the special school, in the day centre, we were expending energy. All this energy was expended in a different context. Back then, we thought that the service system would and could get better if we did all these things. Looking back, however, we realised that the whole of that struggle was carried out knowing that Matthew's life, his very existence was outside our control. At most we were tinkering. The old struggle also had another quality about it. It was diminishing and draining. It sprang from denial and shame, and these things do not bring people together.

The struggle to win the change was very different. We had to look outwards and engage others to join with us. We had to dare to ask. So, we got through our discomfort and called upon others, firstly within and then outside our family. We chose which professionals we called upon and concentrated on individuals who were prepared to make a commitment to change. As a family we needed a range of people. We sought out people to whom we could look for inspiration – in particular other families who had already started on a different road. We used those who were connected to the inside workings of the bureaucracy. We looked for people who would help with reading draft submissions or to accompany us on meetings. We drew inspiration from young parents who gave us energy and spirit.

These are hope-making strategies. People who stand beside you, people who challenge you, people who don't tell you that it's all too much, or that you're looking for the impossible.

Matthew's vision and place of his own now

Matthew has experienced living differently for 13 years. At the core of our vision for Matthew's life is the opportunity to experience freely-given relationships. He and we learned that these kinds of relationships are to be found in ordinary ways. He finds it difficult, however, to develop relationships as easily as others. Matthew does not speak, he needs support in every aspect of his life from the time he gets out of bed in the morning, he has mannerisms and ways of expressing himself which are potentially off-putting, and he can initiate very little.

Because of this we have had to create opportunities and the 'space' for this potential. Matthew lives in a home he can call his own and it is crucially important as it is a natural space for this to happen without him having to do much! Instead of bowing to the fatal assumptions of "who would want to live with him?", "it needs a very special person and they're just not out there", we took a leap and decided to have Math share his home with people without disability and found that there are other people who are interested in sharing.

Some reflections on living with people without a disability

Wonderfully Math has become friends with some of his housemates. This opportunity would never have existed if we had remained seduced by the security of a 24-hour paid care arrangement.

If you are feeling unconvinced, we have 13 years of evidence to support an alternative assumption; EVERYONE has something, a beautiful attribute that is going to help them facilitate a meaningful connection with other people. Your son or daughter, the person you work with, the people you are writing policy about. They have this too. People are able to connect with a person with disability. Why not try this assumption out? We tell you it is liberating. It takes you into a whole other world.

Some things that Math and his housemates have found connection over include action movies, car racing, watching all the football codes, cricket and tennis, bush walking, swimming, kayaking, gardening, cakes and muffins, tea, humour and enjoying a pub meal.

Of significance is Math's first attempt at a small business (as an alternative to his day centre). A previous housemate, Daniel, discovered his passion for native orchids whilst living with Math. Together they grew, tended and sold native orchids at markets.

Looking back, some of our insights are that:

- All of Matthew's housemates have stayed longer

than average staff members.

- Matthew has experienced theft but it has never been a housemate.
- All housemates have fulfilled their basic obligations set out in their lease and some have exceeded these.

Identity

Matthew is a changed man, although it would be unwise to say that his history does not remain with him. For example he still carries some behaviours which have significant impact on his health and his financial status. If not checked, these health issues have the potential to become life threatening. He learned these behaviours as ways of coping with anxiety in a stressful living environment and of boredom. They are ways he has found to stimulate and calm himself. We think of Matthew as someone who has limited functionality, but we don't think of him as disabled.

“Sometimes I have to catch myself. I am chatting away to Math and then I ask him a question. Sometimes I have looked up when I don't get a response. Then I laugh at myself. I have noticed other community members do the same. A shopkeeper asks Math a question. A festival-goer stops to chat to him about something. It's a fascinating moment to observe because Math won't respond or he'll make a noise. What does this say about identity?” (Libby)

Our most significant insight to pass to you about changed identity was only a short time after he moved into his own home. At 26 years old, for the first time in his life Matthew looked in the mirror and gave a great smile and laugh at what he saw.

What are some other tangible aspects of identity?

- Friend to a wide variety of people
- Small business owner – ME & Company which does mail delivery
- Volunteer – at a State Forest and a yearly music festival
- Self awareness and initiator (although his history of dependence and learned helplessness is still strong)
- Substantial reduction in many anti-social and problematic behaviours
- Increased ways of communicating his needs and wants
- Increased daily living skills
- Increased ability to interact with larger groups of people and be in places where there are crowds
- Substantial weight loss
- Inclusion, not just community participation or access.

All these relationships and experiences go beyond Matthew's support needs and they help heal the wounding life experiences which so powerfully shaped his early life. Matthew has taken back his birthright. He contributes to the growth and development of others, and to the wellbeing of our society.

He is a victor. He is creating his place in the world. He is a giver, not just a receiver, and many more people can now add their voice to his future. We wish him well in his future.

Conclusion on individualised support systems

Since Math has moved into his own home he has still required a paid support system. Through this period of change, we have come to view these supports quite differently.

Social policy deems a benign nature to human services, seeing them as unquestionably “good”. We do not now see the human service system as unquestionably benign. We believe like all systems, they are naturally flawed, serving many interests more powerful than Matthew's or our's. Instead we believe in the creation of supports which acknowledge the cornerstones of inclusion, which seek to embed people in their history, birthright and family and which counter the things which might make people vulnerable.

We see that human services may have a role, not that they automatically do. Where they do have a place, families and people with disability must adopt a critical and questioning perspective (not to be confused with fatalism or negativity). Matthew's story powerfully shows what happens when such systems are unquestioned by those closest to him. We also see that if they do have a role, this needs to be at the invitation, creation, discretion, direction and guidance of people and their families.

Lastly we see that there are many people involved in human services who can assist families and individuals think through what supports they need, assist them to gain insight and perspective. But such assistance happens when power is shared and when constructive and open relationships exist between parties.

This view is reflected in the support arrangements we have created around Matthew. It now involves his support funding going to a service of our choosing which delegates – to him and us – the authority and control around all aspects of the paid support system. We are the vision builders, direction setters and decision-makers. These kinds of supports have been variously termed consumer and family-governance models. They need more emphasis in government policy and funding priorities.