

## Matthew's Story: Creating Place

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*Matthew's story was written by his mother Judith and sister Libby. This article is a shortened version of a paper presented at the One Person at a Time conference in Melbourne in 2008.*

This story attempts 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 story are about how environments can disable (or enable) people, and about the process of change for a family and about liberation.

### **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 has a strong history in Australia. 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 say (and we use metaphors for light and dark in his story).

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, in 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.

### **Shadowlands**

Very early in our family's 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 two hours drive 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 the 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 nothing 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 but 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 Matthew might be there—he was only 6—it was the 'done' thing.

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 we were doing the right thing?

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.

## **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.

In coming into a 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.

## **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 relationships 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 four years—drafting submissions in the small hours of the morning, phoning, attending meetings, talking to government personnel, negotiating, researching, writing reports and badgering.

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 to meetings. We drew inspiration from young parents who gave us energy and spirit—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. These are hope-making strategies.

### **Matthew's vision and place of his own now**

Matthew has experienced living differently for 13 years now. At the core of our vision for Matthew's life is the opportunity to experience of freely-given relationships. He and we have 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 do. 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 Matthew share his home with people without disability and found that there are other people who are interested in sharing.

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 and boredom in a stressful

living environment. 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'.

Our most significant insight to pass to you about his changed identity occurred 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.

Some of the changes in Matthew include that he is a friend to a wide variety of people; he is a small business owner—ME & Company which does mail delivery and a volunteer—at a state forest and a yearly music festival.

He is developing self-awareness and his ability to initiate (although his history of dependence and learned helplessness is still strong).

There has been a 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, and increased inclusion, not just community participation or access.

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.

### **Conclusion on individualised support systems**

Since Matthew 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 ours.

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. We believe that they need more emphasis in government policy and funding priorities.

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