Journeys to a better life

This document has been written on behalf of Community Safeguards coalition (CSC). CSC is a coalition of people with disabilities, families, allies and advocacy agencies who agree to the mission and purpose of CSC, which is:

> *To promote people with disabilities having the equal right together with appropriate support and resources, to the same range of lifestyles as other people by safeguarding against legislation, policies and practices that limit or deny their fundamental rights.*

The Convention on the Rights of Persons with Disability (CRPD) provides a clear vision for the future –

a future that ensures that people with disabilities have a right to live and to participate in their community with the support they need and to ensure that any assistance provided to them should be based on their own choice and aspirations and that services for people with disabilities should support living and inclusion in the community and aim to prevent isolation or segregation from the community.

The journeys undertaken by people with a disability and their families in the stories that follow show the difficulty in fulfilling people's human rights when they are placed in situations that could be called 'institutions'.

A useful definition of 'institutions' is:

> *An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. It is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.*[1]

AIM

It is the aim of this document to trace/capture the lives of five people with disabilities who have found themselves living in 'institutions', the negative impact this had on them and their families and their subsequent journey from an institutional setting to living a quality life of their own choosing. It is hoped that what has been 'learned the hard way' by these people and the steps that were taken in order to ensure the vision for the person with a disability was fulfilled will be of benefit to other families who may find themselves in similar situations.

METHODOLOGY

Face-to-face interviews were undertaken with four families and one interview with two brothers with a disability as well as an interview with an ally of these two men. The stories were written up and provided to each one for approval and/or correction. Permission has been given to publish the stories.

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[1] European Coalition for Community Living {ECCL} Focus Report 2009

VICTORY OVER MADNESS • CAMERON’S* STORY

“Victory over Madness” are the words used by a young man called Cameron*.

The ‘madness’ began when Cameron went to live in a purpose built house with 4 other men of various ages, ranging from 30 to 50, who all had what is called ‘challenging behaviour’ and in Cameron’s case, autism. As Cameron’s mother put it “they knew each other, but they didn’t choose each other”. These men were supported by staff from a service provider and the men or their families had no choice or input into selecting the staff. Families got a very clear message that they were not welcome to visit as this was seen as interference and if they wanted to visit, they must first make an appointment. The environment was not welcoming, in fact it was threatening.

Cameron came home to his family once a fortnight. It was on one of these visits that his mother noticed Cameron seemed to be in some discomfort with his back. When she looked, she found large “railroad tracks” type bruises all the way down his back. Horrified, she looked further and found almost his whole body to be covered in bruises – he was black and blue all over. This was immediately reported to the service provider, but no action was taken: the response being “nothing happened, the staff didn’t do anything, he must have fallen over”. The family reported the incident to a higher authority, but Cameron was deemed to be an “incompetent witness” and the case was dismissed.

The “madness” escalated. The family took Cameron out of the house and brought him home to live. However, this experience had greatly traumatised Cameron and he was full of rage and hurt and mistrust. Cameron’s behaviour was totally out of control. He threw things, he smashed things and would throw himself at people. He hyperventilated in fear. The family, particularly Cameron’s mother, received very little support from the medical profession. Cameron’s behaviour was blamed on her: she was told “you are one of those ‘freezer’ mothers, cold and emotionally unavailable to the child”. She was blamed for everything, leading to a sense of guilt and failure. This went on for 5 years. The family managed to obtain some support from a service for a few hours each day while they tried to attend to their own significant health issues brought on by the stress of living under such conditions.

Some light appeared. Another mother put the family in touch with an advocacy agency who supported them to achieve their vision for Cameron: “to live in his own home with support and lead a meaningful life with friends and family around him”. They never wavered from this vision and were determined to see it fulfilled for Cameron even if “it cost us our lives”. A public meeting was arranged and about 10 like-minded families formed an organisation which became incorporated. A Department of Housing house was found for Cameron close to the family home. Funding was sought and a package granted after a great deal of intense lobbying.

It took 6 months for Cameron to make the transition to his new home. He had become agoraphobic. His parents spent the first 2 years with Cameron in his new home to help him adjust to his new surroundings, to accept staff being in the house and to learn to trust again. They gradually withdrew starting with a few hours and building up to a day or two and finally they returned to their own home.

“Victory”. The vision the family held fast to for Cameron, despite incredible odds, has been achieved. He is living in his own home, he shows no sign of aggression, he is now able to communicate through facilitated communication, he has a circle of friends which is widening all the time and he is slowly overcoming his agoraphobia. In this environment, Cameron’s creativity emerged. He is a talented, successful artist who has held many exhibitions and sold his paintings.

“People with disabilities and their families, friends and carers reported daily instances of being segregated, excluded, marginalised and ignored. At best they reported being treated as different. At worst they reported experiencing exclusion and abuse and being the subject of fear, ignorance and prejudice”.

*not his real name

IT NEARLY KILLED US • SAM AND DAVID'S* STORY

This is a story with a happy ending. It wasn't always that way. It has been a difficult journey for these two brothers, Sam and David, who have muscular dystrophy, to achieve the life they want.

> *Up until 2006 they were living with their parents and receiving a small amount of in-home funding and therapy services from a non-government organisation. Their parents were becoming very tired and it was at this time, that Disability Services offered them a 4 bedroom house. A service provider was allocated to them without consultation: they had no choice. They were told there would be one other person coming to share. This person arrived after about 3-4 months, with no trial period to ascertain compatibility. He had completely different needs to Sam and David and his behaviour caused difficulties within the household. To make matters worse, another man with similar behavioural issues was placed in the 4th bedroom. This person showed his discomfort and unhappiness through aggressive behaviour, abusing people as he sat outside drinking alcohol.*
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> *This situation became a living nightmare and there were times when Sam and David would lock themselves in their room feeling as though they were "in a mad house". They had no choice in support workers and if they happened to build rapport with a worker, he or she was moved on as the policy of the service provider was that it was "unprofessional" to be close to the client. However, with other workers that the service provider sent there were some instances of abuse and inappropriate sexual language. This was reported, but was not believed and therefore not followed up or resolved.*
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> *Sam and David told Disability Services that 'they didn't want this life' and wanted to move. Rather than move Sam and David, the other two people were moved out and a person with intellectual disability was moved in. The household became more harmonious and the three became friends. This harmony did not last long. A person with very high support needs was moved in. His needs were not able to be met in this environment and he became very aggressive and abusive, smashing things and turning the lounge room into his bedroom. Once again Sam and David felt like they were "in prison" having to lock themselves in their room.*
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> *This situation was the 'final straw' and as Sam said "it nearly killed us". They were traumatised and depressed and sought help from a psychologist.*
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> *A formal complaint was made by Sam and David to Disability Services in regard to the lack of dispute resolution by the service provider. A few weeks later Sam was given an eviction notice by the service provider for a trivial matter and had 30 days in which to leave the premises. This would also have meant that Sam would lose all of his support. It was at this point that family became more active and an advocate became involved. Their situation eventually went to trial. The judge ordered a 6 week delay on the eviction. During this time, Disability Services offered another group home as the only option available to them. They refused this offer and 'stood their ground'. Because of strong political and advocacy support Disability Services agreed to increase their funding with the proviso that Sam and David try to reduce their costs as much as possible – which they did.*

The happy ending came about when a Department of Housing house was found not far from their parent's suburb and it was agreed that Sam and David could self-direct their own funding. They are now making their own decisions about engaging staff and are taking control of their lives.

*not his real name

SEIZE THE MOMENT • BARBARA'S* STORY

This is the story of a family who felt that often it was by 'seizing the moment' that their loved daughter and sister is now living a happy and meaningful life. This is how is happened:

> *Barbara moved out of the family home at the age of 20 into shared accommodation, living with other people with a disability along with people without a disability. This was a very pleasant time for Barbara until things started to change. The service supporting the household started to formalise and insist on rules that were developed for the 'health and safety of workers' and there was no consultation with the people who lived together. The community that was developed including household members, families and local community was edged out and a service culture became dominant. The service provider decided to demolish the building the people lived in to build a block of units. Barbara's family was told, once again without consultation, that Barbara was to live with a person who the family felt was a totally unsuitable housemate for her. This resulted in an unfortunate falling out with the person's family who felt personally rejected by Barbara's family. As a result of much negotiation, Barbara was accommodated in a unit of her own with shared support staff – this worked out well for some time.*
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> *Things changed again: Barbara's parents had always wanted to live near the water and finally made the decision and moved to a coastal city – a couple of hours away from Brisbane. Barbara's support circle met regularly to find ways to best support Barbara as her parents were unable to provide the same amount of support they once did. The family became increasingly frustrated with the lack of open and transparent communication with Barbara's support staff. It was decided to move Barbara to be closer to her parents where they could claim their authority over Barbara's support. The family did not put this venture into the 'too hard' basked, but instead 'seized the moment' and began to focus on how to make this possible. This is what happened.*
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> *The family engaged a consultant to facilitate a discussion with Barbara's support circle to brainstorm strategies on how Barbara could not only move closer to her parents, but also have her funding individualised in order to have more choice and control over her life. The following strategies were put in place:*

First strategy was to call a meeting with the service provider. The family needed to know how much funding Barbara had received: this was never disclosed to the family before – they had only been told that Barbara was entitled to so many numbers of hours. This information was vital to the family as they could then work out a plan to support Barbara on that money. The service provider was reluctant to give this information. However, once again the family 'seized the moment' and insisted on their right to have this information: they won they day through sheer persistence!

The second strategy was to ask the advice of a 'key person' in Disability Services who they knew to be sympathetic to their situation. The advice given was, firstly, to ensure the families with whom Barbara shared accommodation were consulted about the proposed move and new funding arrangement, obtaining their support to this happening. Secondly, to document the benefits to Barbara by making this move as well as developing a plan to ensure Barbara was well supported both formally and informally with the funds available.

The third strategy at this point was a very important decision the family needed to make. In order to make this happen and overcome the resistance of the service provider to release the funds to Barbara, the family decided to take, what they called "the easy path", i.e., rather than going into negotiations with the service provider in an aggressive manner, telling them everything that was 'wrong' with their service (deficit model), their strategy was to encourage the service provider to show true leadership and to see how beneficial this would be for Barbara (positive model).

The fourth strategy was to arrange a second meeting with the service provider and importantly, invite the 'key person' from Disability Services to be present, thus ensuring that the strategy had the endorsement of DS. What transpired at this meeting, was a 'trade' i.e. the service provider kept Barbara's funding and filled the vacancy left by her leaving and DS offered Barbara the possibility of 'new' funding. A proposal *went to a funding panel, along with the more flexible individual plan and it was approved. The proposal included demonstrating how Barbara could be supported to live in a home of her own with the equivalent of the 'magic' benchmark of 65 hours per week and 7 sleepovers. The proposal demonstrated how, with a combination of informal support and targeted funded support to meet Barbara's support needs, that this was possible.*

The fifth strategy was to move Barbara into her own unit which the family purchased. As well, a trust was set up. At this point, the service provider was still 'in charge' of support staff and certain regulations made flexibility more restrictive. Once again, the family 'seized the moment' and decided the best option would be to self-direct the funds.

The sixth strategy was to employ, once again, the 'positive model' of negotiation and put forward their case in a way which centred on the benefits to Barbara. This strategy was successful and the funds were transferred to a Host Provider and the family took over the responsibility of self-directing.

The happy outcome of this story is that Barbara is now living in her own home with staff she chooses herself; she is making more and more decisions for herself and is included in all discussions regarding her daily activities and what she wishes to do each day. Barbara is becoming known and included in her local community and she is involved in mainstream activities such as art class and a singing group and has a great group of friends.

*not her real name

TANYA'S* STORY

This is a story of a family's journey through the sorrow of receiving devastating news to a successful outcome for their daughter, Tanya.

> *At the age of 17, Tanya contracted a virus which put her into intensive care on life support. This virus left her with acquired brain injury (ABI. She lost her speech, needs assistance with everything and is in a wheelchair. Also, this virus caused random bone growth, fusing her hips to her legs causing incredible pain. The family was told the only option for her was a nursing home. This option was rejected by Tanya's family.*
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> *Tanya was then placed in a rehabilitation facility. Her needs were assessed there which took over a month to complete. In this time, Tanya had no therapy compared to therapy twice a day when she was in hospital. Unfortunately, there was a high turn-over of staff, particularly therapy staff, so there was no consistent treatment. Tanya made no progress in this time, in fact, her abilities regressed.*
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> *The conditions at facility were of concern to her family. There were 4 people in Tanya's room some of whom had behavioural issues, such as poking Tanya in the eye and taking her food. There were no doors on the toilets, so there was no privacy. Tanya's bed was far from the nursing station and therefore a lot of the things done to her went unseen. Once this was pointed out to the staff, she was moved closer to the nursing station. However, Tanya's specialised bed was given to another high care client – without consultation with the family.*
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> *These conditions alerted the family to the need to be constantly vigilant. Tanya's mother visited her every day and night for nearly 2 years to ensure the safety and well-being of her daughter.*
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> *Although other families who had loved ones in the facility gave each other support, Tanya's mother felt she needed some help to enable Tanya to leave the place and bring her home. An advocacy agency was contacted and became involved. With the advocate's help the family was placed on the Department of Housing list and funding was applied for so that Tanya could get the support she needed to return to living at home with her family.*

Tanya spent 1 year and 9 months at this facility before she was able to move in with her family into an accessible/modified home with funding for support staff.

*not her real name

ROBERT'S[*] STORY

This is the story of Robert, whose long journey began in 2007 when at the age of 28 he was involved in a car accident.

> *His journey began in hospital where his condition was diagnosed as 'acquired brain injury' (ABI). As a result of his accident Robert needed to use a wheelchair, was non-verbal and had to be peg fed: he expressed his frustration with his situation through his behaviour: he lashed out physically, pulling out his peg and became antagonistic to all assistance offered. However, because he received very little therapy, his condition was deteriorating: it was suggested to his family that a nursing home was the only option. This option was rejected by Robert and his family.*
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> *The alternative was a rehabilitation centre. The eligibility for this centre was a person "had to do something on command" and the therapist at the hospital felt that Robert had the potential to improve and take advantage of what could be offered in rehabilitation. Therefore, in 2008 Robert was moved from hospital to a rehabilitation centre. Robert originally shared a room with 3 others which was eventually reduced to 2 others. Every day, Robert's family – his father and partner, his sister and his older brother would visit him. His sister stopped work in order to maintain the vigilance and support that Robert needed. It became evident that much of Robert's personal care was not adequately attended to and there were problems with his intake of food. Once again, Robert expressed his frustration with his situation by physically lashing out.*
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> *In 2009 Robert was transferred to another rehabilitation facility further away. His peg was removed and he started to eat well. He was getting outside in his electric wheelchair and enjoying some freedom. However, when it was discovered that Robert was going outside the grounds of the facility in his chair, he was switched to a manual chair which he did not have the strength to push and was thus effectively stopped from any independent activities. He was put in front of a T.V. all day. Robert's family also discovered him at one time lying in his own vomit and another time found him sitting in his chair soaked through with urine. At this time, Robert became quite depressed due to being confined and to being moved from one place to another within the large complex. He stopped eating adequately.*
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> *Robert's sister became increasingly angry with the way the 'system' was treating Robert. She made contact with an advocacy agency and also attended a Community Cabinet meeting. It was at this meeting that her anger and distress at her brother's condition burst out and she told the Members of Parliament who were present just exactly what was happening. As a result of this meeting, her local MP wrote to the Minister for Housing and the Minister for Disability Services. The reply she received was that Robert was not a priority for either housing or individualised funding – a group home was the only option. The family knew that this would not work for Robert. Robert's sister had a contact within Department of Housing and through much advocacy and negotiation, Robert finally obtained his own residence and individualised funding and moved out within 6 months. His funding is now self-directed by his sister.*

His sister reports that Robert's memory is improving all the time, he is less aggressive and he is less anxious now that he is in his own home and leading a life of his choice.

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[*] not his real name

PATHWAYS TO A BETTER LIFE

The following is a compilation of the pathways people took in order to achieve a better life. It is hoped this may be of assistance to families who find their loved one in a similar situation and are looking for a way out:

- The focus always remains on the person with the disability: have a very clear Vision of what sort of life you want for your family member and what support is required to achieve this vision: both formal and informal supports. The Vision must always remain at the forefront of everything you do. Do not be deterred from this by others telling you that it is 'not possible': never waver from your Vision
- Give a lot of thought as to 'why' you want to do this: what is the 'problem': is it because your family member is, for example, unhappy, being abused, not receiving the support he/she needs – what is the issue. Disability Services has stated in its Guidelines for "Individualisation of Block Funded Support Arrangements" that it will consider individualisation of block funded arrangements "where there is reasonable and just basis for individualisation".
- Establish a network around your family member: ask yourself 'who are the people who need to be brought into the conversation' – family/allies – others who maybe 'in their corner': advocacy comes in all shapes and forms. Without this support around your family member and yourself, you become isolated and vulnerable.
- Once you have this support network, break the problem up into categories, for example: "what is happening now", "what is non-negotiable, e.g. my family member will not go into another group home", "what do we want to happen" "what is the next step" and "who do we need to help us in solving each of these problems": who are the key people in relevant government departments who will listen and use their influence to assist your family member achieve their Vision - it may be someone you know in the Department of Housing or Disability Services or your local/federal MP
- Information is power: don't always rely on what others tell you, find out information for yourself
- Know your rights. Australia has signed the U.N. Convention on the Rights of Persons with Disability. This means that all States and Territories are obliged to implement these rights. Article 19 of the CRPD specifically states that people have the right to live where and with whom they choose. This is what is called a 'realisable' right, i.e.it is not a right that can be implemented over a long period of time: it should be implemented now
- Don't waste energy on anger or retaliation: This is not productive and can have the effect of alienating those who want to be on your side.
- NDIS is just around the corner – be prepared – start planning for your loved ones future
- Persistence and even more persistence pays off
- Accepting less than what is acceptable comes at a cost, Not accepting less than what is acceptable also comes at a cost – either way there are costs involved!!!
- Shocking situations call for radical action

On behalf of CSC I wish to thank all those who have shared their story, for giving such a rich description of the hardships and trauma that they have experienced. However, within those stories, there have also been 'alternative' stories, i.e. we have heard how these people have put into action their hopes, their vision, their skills, their commitment and their care for their loved one in order to reach a solution. It is difficult to take action when the burden is heavy, but with the strengths they have displayed, they have overcome the hardships and reached out for solutions. I acknowledge and respect their strength and determination and their great generosity in sharing with me their personal journeys to a better life.

Carol Holt

Chairperson

Community Safeguards Coalition

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