

[Telling the Untold](#) is published by Community Resource Unit (CRU).

Excerpts from Telling the Untold

Preface

The Challinor Centre was a large medical institution which, like many from the era, was created as an asylum for people living with mental illness. The asylum was started in 1877 and in 1938, with the proclamation of the *Backward Person Act*, its purpose changed to provide services to people with intellectual disability. The centre grew and by the 1960's had over 600 residents.

In the mid-1990s, the Queensland government began a policy described as 'institutional reform' for state institutions and the centre was marked for closure. This reform was similar in both conception and implementation to a number of deinstitutionalisation processes that had already occurred in other countries and in other states of Australia.

In 1996, Community Resource Unit undertook a project called Focus on Families which was to provide support to families of the men and women who were residents of the institution at that time.

As families were struggling with the announcement that the centre was to close, it became clear to CRU that other, earlier struggles had taken place in the lives of those families. Those earlier experiences had remained untold and the pain that had been caused by the experiences, and by the silence, continued to be a source of anguish for almost every person with whom we worked.

Their anguish arose out of the fact that the service system provided institutions as the solution to the problems that the families were experiencing in that earlier period. As a result, the family, as an entity, was ruptured. The narratives in this book bear witness to what happened.

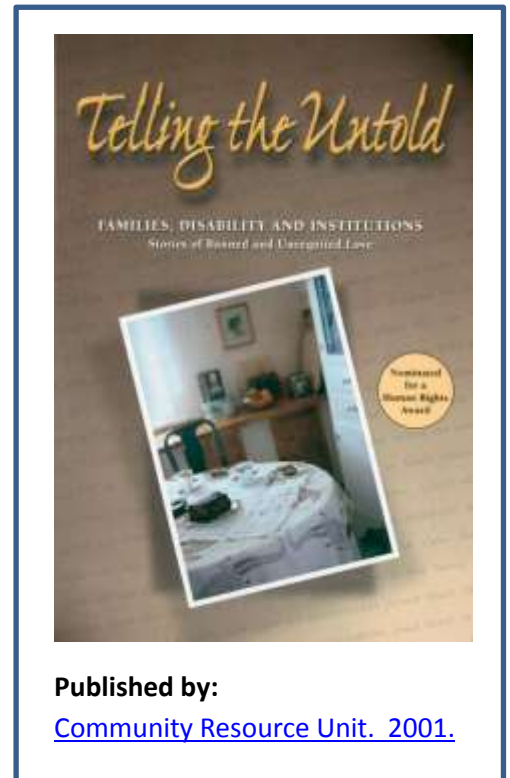
The Narratives

Some of the narrators come from rural communities, while others come from large regional centres or metropolitan Brisbane. Overall, it is a group of families that has all the common similarities and differences you might expect to find in any random group of people. Without the common experience of having a family member who spent many years in an institution, they might never have discovered their strong connection with one another – a connection that was forged through the pain of separation from a loved daughter, son, brother or sister.

In all, twelve families shared their stories for the book *Telling the Untold* and we share three of them here in this paper.

Libby

Libby was born in 1964, the second of four children born in four years. Libby's condition was not diagnosed until she was fifteen months old – a diagnosis that changed from "autism" to "mental retardation". Libby went to Challinor when she was ten and was there for about twenty-three years. When we met them, Libby's parents were jubilant about Libby leaving the institution and moving close to where they lived. Libby lived in a small group-house and received support from a local non-government service provider. Things did not work out well and Libby moved back to live at her parents' small house to await a new arrangement. Most of her life, Libby



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had been plagued with complex medical problems and was quite frail. Libby enjoyed some months with her parents, but she died in November, 1998, almost two years after leaving the institution.

Reneé

Reneé was born a healthy baby in 1941 but became ill with meningitis when she was nine months old. As a result of a severe infection, Reneé developed hydrocephalus. Her condition was initially ignored by doctors, and this neglect caused her to become severely disabled and totally immobile. Reneé's father died suddenly when she was four years old. She went to live at Challinor at the age of twelve when the strain of her physical care became too much for her mother, who was pregnant following a second marriage. Reneé lived at the institution for over forty-five years.

Patricia

Patricia was the oldest of ten children. She was admitted to Challinor in 1977 at the age of twenty-six. Her entry to the institution came about after the death of an aunt with whom she had lived since the death of her mother. Contact with her sisters and brothers declined over the years but closeness was re-established when another aunt, who had regularly visited Patricia at the centre, also died. Patricia's sister, Margarete, reconnected with Patricia, and became aware of the abuse that she suffered at the institution. This prompted her to work towards getting Patricia out, and she moved from the institution in 1996, after eighteen years of residence.

Entering

In spite of anxiety, disappointment and stress, the vast majority of families in the general community who have a child with a disability, love and accept their child and want to care for that child. Families who have a child with a disability behave like other families, asserting their essential normality as they tackle problems. Families can be amazingly resourceful too, but they benefit enormously when well-timed, practical support is received.

In the 1950s and 1960s, husbands were still regarded as the breadwinners and wives were regarded as being responsible for household tasks and the emotional support to the whole family. The care of children, with or without disabilities, was seen primarily as the responsibility of the mother. Rather than receiving practical help, mothers were often blamed in numerous ways. The implication was that they were undeserving, either for having an impaired child in the first place, for not accepting that the child was impaired, or for being a neurotic parent because of a desire to do something about it.

In some families it was the death of a mother that was the catalyst for institutionalisation. For example, Patricia badly regressed when her mother died and according to Margarete, it was only then that her sister's disability became apparent. She says:

MARGARETE: At twenty-six years of age it all stopped for Patricia. Things that were normal just ceased. After Mum died, Patricia went through a really bad stage. She was hard to handle and went to live with an aunt. Within a year, that aunt died. There were four deaths in that year – our mother, two of her brothers and her sister. Patricia was put into Challinor when our aunt died.

Libby's mother Marie shares a moving narrative of a family under great stress. It is also a story about a woman who lovingly cared for her daughter, as well as three other children, and found herself less and less able to cope. The very fact that she believed that it was up to her to cope by herself prevented her from actively seeking help.

MARIE: Our story is an emotional one. I suppose everyone's is to a certain extent. I'm telling it now, after Libby has died. One thing I remember is that we never went out because we couldn't take Libby anywhere. She would wreck everything. We had gates at all the doorways because she would rip everything. She was happy enough, it was just that she never stopped. She was constantly on the move and we couldn't train her. We nursed her a lot.

We were really struggling financially. We didn't have a car. We lived in the outer suburbs at this stage. My mother would come over and she was a great help with the housework. We virtually had no help at all outside of Mum.

All I was doing was looking after four children and a husband. Libby was very difficult to look after at that time. I was up until midnight doing the housework because I never had time during the day. I couldn't sleep anyway. I would cry every night because I had the next day to face and I knew it was going to be just the same.

A young social worker came out from the city and talked about Challinor and advised me to put Libby's name down. She said there was a long waiting-list so it would be a long time before anything would happen.

A few weeks later Libby's name was put at the top of the waiting-list for the centre. They must have thought the situation was pretty grim. When I look back, even though it was difficult, it wasn't that grim. I suppose it's easy to say that now that she is gone. But I feel that if I'd had a bit more maturity about me, I would have hung on. She was nine and I was thirty-two.

In Marie's case, as in most other cases, it was the intervention of professional practitioners that signalled the commencement of actions that would lead to the gates of the institution. In their long, unrewarding search for support, parents got caught up in travelling to and from numerous sources of possible assistance.

One of the most disturbing themes that arose out of the work of the Focus on Families project was that of the overwhelming heartache and loss that was experienced by parents and siblings when they were separated from the member of their family who was lost to them, through institutionalisation.

MARIE: I got a call to say that Libby could go to Challinor. It shook me. Reality struck. I was supposed to do this. John came home from work that afternoon sick with a high temperature and he went straight to bed after his shower, without his tea. I didn't have the heart to tell him.

When we moved to Ipswich I used to go up to the centre each day to assist Libby with her lunch. The staff asked me to stop coming because they said she wasn't settling down very well. They concluded that it was because I was visiting so regularly. We would bring Libby home for a few weeks at a time, mainly so the other kids could see that she was still part of our family. She was still walking at that stage.

We never really came to terms with Libby being at the centre. Taking her back was always so hard. Everything became a ritual. It was so painful. Our relationship continued to deteriorate – John withdrew and I just went on cooking and cleaning. Just surviving and looking forward to Libby coming home on the weekend – and pleased in some ways when she went back, because it was so hard. The other kids didn't have much of a life when Libby was there. I couldn't get involved in their school activities.

All of the families say their emotions and thoughts were disturbed and painful following the departure of one of their members to the institution. It was not possible to continue family life as if the person had never existed, although advice to do so was often proposed by professionals.

When hearing families' accounts of visits to the institution it is hardly surprising to learn that the frequency of visits declined over time. Some of the physical and emotional barriers that arose during visits are described in the following passages by different narrators who give us a sense of the unwelcoming culture that operated at the centre.

GWEN: I had to apply at the office for a pass to be admitted to see René. The ward was surrounded by high fences and we had to wait for the gate to be unlocked and then this was repeated for the door. The same procedure applied to departure from the ward. I always wondered if she was safe.

We didn't feel welcome. We actually felt there was hostility towards us. They seemed to see parental interest as parental interference. I was supposed to let them know if I was coming to see René, but I didn't. They couldn't stop me. René was my sister and I wanted to see her.

All formal systems have their own culture; that is, a system of shared beliefs, values, and customary ways of behaving. The term “institutional culture” refers to the fact that what happens in an institution seems to emanate from unwritten rules about the way things are done, the language that is used, the codes of behaviour and hierarchies of power. Some expressions of institutional culture are covert and others are overt.

A significant aspect of the institutional culture of the centre that was described by the majority of families was the perception that families, particularly parents, were thought to be part of ‘the problem’. Parents sensed that judgement had been passed on them, whether that was as uncaring or incompetent parents who were not able to care for their own family members, or as people who were lacking in some way, and therefore not deserving of having a so-called ‘normal’ son or daughter. These judgements were felt as much by parents who frequently visited the institution as they were by those who were able to manage only occasional visits.

Other families reported that a lack of respect was a constant experience of institutional life. Dorothy gives an example of a general lack of respect for her sister’s individuality and its somewhat bizarre outcome:

GWEN: They even changed René’s name, although not deliberately, but it is an example of how they took over control without consideration for the family. For almost forty years René was known as ‘Reenie’ at Challinor. When we would ask about René, staff looked at us blankly until we also referred to René as ‘Reenie’.

Many of the families we worked with during the project reported their distress and disbelief at the changes they saw in their brothers, sisters, sons and daughters once they moved to the institution. They spoke of always being distressed by their appearance.

In the following passages René’s brother-in-law, Rod, speaks frankly about visits to the institution over an extended period:

ROD: When I first heard about René I thought of her as almost an alien – lying on a bed in a mad-house with a big head. There was all this security and our kids weren’t allowed into certain areas. You would have to give plenty of notice so that they could bring her out and when I first started visiting with Dot, René would be brought out on a mobile bed.

I think the first time I saw René I felt like picking her up and carrying her out – I even assessed her weight. But then we realised that we didn’t have the resources to care for her.

Looking back I realise I always related to René as if she was a little girl. We used to take her nursery-rhyme tapes and dolls and things like that. It just didn’t enter our heads that this ‘child’ had developed reasonably normally until she was about eleven or twelve. She had functioned intellectually and had played with other children. But her development had frozen. From the point of her institutionalisation there was simply no more relational development for her.

Many people observed how their family members lost skills while living at the institution. In the following example Margarete recalls that her sister’s everyday use of basic skills had been central to her identity within the family:

MARGARETE: Patricia used to look after us as kids. We used to live very basically back then. We didn’t have electricity. There was an old wood stove that Patricia was perfectly capable of using. She used to cook up all sorts of things, whereas nobody trusted her to do those things in that place.

For those who were institutionalised, the full impact on each person was not to be fully realised until much later. Margarete reflects on the loss of 'ordinariness' from her sister's life, after she went to the institution:

MARGARETE: It seems that normal things stopped for my sister when she went to the Centre. She has missed out on seventeen years of maturing in normal society. Instead she had to learn how to survive in an institution. It took away a lot from Patricia. She went backwards so much that her disability became obvious. For the twenty-six years she was with us in the family, she was never thought of as being different and she was never treated differently. It just horrifies me to think of how she must have felt when she first went to that place and how she viewed what was happening. It constantly goes through my mind.

Margarete says she felt torn apart by the revelation that her sister had been physically abused while at institution. She was extremely angry that her attempts to achieve justice were thwarted by a system that rejected the credibility of her sister because of her intellectual disability. Margarete recalls what she had to say at that time to the centre's administrators:

*MARGARETE: This woman is completely innocent. Look at her face and tell me that something has not happened, when she is completely blue with bruising. And you are telling me that the person who did this is a person who is continually 'victimised' by allegations!
That's why, in the end, we decided to get her out of there and take her away to where she will never have that treatment again. Hopefully she can live out the rest of her years without ever knowing such a place again. Every time I saw her at Challinor, she would say, "I hate this place, darling". When I took her back after a monthly visit, she would say, "I hate this place, darling, I don't want to go back".*

Many families reported that they were confused by what the government announcement about the closure actually meant. Some families found that the communication from the government was neither clearly conveyed nor clearly understood.

Renee's sister Dorothy describes the initial reactions of her elderly parents:

GWEN: Mum in her late seventies, and Dad just over eighty years old and racked with cancer, understood this to mean that they were to take René home with them to their small one-bedroom apartment. Little was done at first to allay their fears and the whole family thought the idea quite ridiculous. Eventually the government started to get their act together and actually talk to families. It then started to make sense.

The following reflections illustrate the mixed feelings, after such long separations, that were felt even by those who could grasp a vision of the possibilities for their family members leaving the institution.

MARIE: When we heard that Challinor was closing and that Libby would come home, we rejoiced. We never thought it would happen. John and I had talked about the time when the other kids would be off our hands and we could bring her home for good. But it never happened that way... John realised that we would never be bringing her home because we were getting older.

The experience of hoping, planning, and waiting for a family member to leave the institution was an arduous and slow process, punctuated by high points and low points. Many families discovered that leaving the institution was only the beginning; it was to be the start of a new set of challenges as well as a new set of possibilities.

Some families found that support and encouragement from others was not always available after the person left the institution. This meant that a great deal depended on the level of commitment from the particular service organisation that provided support to their family member now living in the community.

Margarete removed her sister from the institution and brought her into her own family home. Patricia lived there until she was able to move into her new house, provided by the Housing Department, and supported through funding from the Institutional Reform budget. This was a very difficult time for Margarete, who had a family of four children, but she was determined that her sister would not return to the place where she had suffered brutalisation. Margarete provides a picture of how things are changing for Patricia as she enjoys her own home in the community, close enough to her family to maintain strong ties and practical support:

MARGARETE: Now it's wonderful. She is not intimidated now. She loves it. She goes to the movies. There is nothing restricting her. She enjoys going out for coffee. She either goes out with a support worker or another man who shares the house with her, as well as the support worker. She also goes to a craft centre. Her life is more normal now. She will come up here to our house and after a while will say, "I want to go home now".

In an earlier section of the book, the loss of skills that commonly occurs during institutionalisation was discussed. Margarete, who had observed such losses in her sister, has begun to see a reversal, saying:

MARGARETE: I was confident that Patricia could do all those things again, given the opportunity. She was confident herself and she picked up those skills rather quickly. Amongst her family she was confident. She was relaxed as well. It was nothing for her to go and make herself a cup of coffee. The last time I went down to Patricia's house she was outside hosing the garden. She is slowly picking up her skills again. She had lost touch with a lot of her day-to-day skills by being in that place. They took all her privileges away and removed ordinary things. That's what I don't understand about those places – people lose skills.

It was nothing for her to get up at two in the morning and get herself a feed. She is capable. She does need someone around to make sure she's switched off the stove and that she's eating well. With Patricia it's a matter of showing her things and repeating things slowly. When she did inappropriate things like eating two litres of custard, I just sat with her and explained why she shouldn't, and she took it from there. There was no problem after a while.

Dorothy describes the personal development that took her from being a passivist to being an activist, to use her own words. From a point where she accepted the control of institutions over those who lived there, and even of families themselves, she is now actively involved in helping to shape what happens for her sister, Reneé, who now lives in the community. It is interesting to compare the following two statements made by Dorothy: the first is a recollection from an earlier time; and the second is a recent reflection.

DOROTHY: As we grew up, most of our friends never even knew about our big sister. You really didn't own up to having a 'retard' in the family, and as she lived at the institution no one could ever get to meet her, or know her. If you did speak of her there was really no proof she existed. She was hidden away. An increasing acceptance of people with disabilities within our society means that we feel free to talk about Reneé, and I do. I tell everyone who wants to listen, and those who don't. I want to tell people about her and our plans for our future.

In Patricia's case, the contrast between her former life and her present life has helped Margarete to more fully understand the experience that institutionalisation had on her sister. She says:

MARGARETE: Before I had my eyes opened to the culture at Challinor, when Patricia was unwilling to go back to the Centre after a visit, I used to think, "What's the matter, Pat? You get three meals a day and a bed". Now I can understand why she used to say, "I don't want to go back, darling". It all makes sense now.