

FORGOTTEN AND FOUND

Kim Walker



FORGOTTEN AND FOUND

My Life Story

by Kim Walker

As told to
Kathryn Knight
and Cristina Ricci



Council for
Intellectual Disability

© 2015 Estate of Kim Walker, Jim Simpson

ISBN: 978-0-9943735-0-2

Published by

NSW Council for Intellectual Disability

Level 1, 418A Elizabeth Street

Surry Hills NSW 2010 Australia

Phone (02)9211 1611 Toll free: 1800 424 065

Email: mail@nswcid.org.au

www.nswcid.org.au



Design by Kathryn Knight

Contents

Foreword by Jim Simpson

Preface by Kathryn Knight

1	Introduction	1
2	My early years	5
3	My years at Stockton	13
4	Finding independence	21
5	Finding my voice	39
6	Finding respect	53
7	Two important people come into my life	67
8	My parents come into my life	83
9	The past catches up with me	103
10	On my own	119
11	Losing my parents... again	129
12	Where I'm at now, mid-2011	149


Afterword by Faye Druett
and Jim Simpson

List of acronyms



*Balloons released into air ascend
high into the sky at the close of a picnic of
friends at Long Bay, NSW, to commemorate
the first anniversary of Kim's Memorial
February 2014*

Foreword

im Walker was an extraordinary advocate for people with intellectual disability over 30 years. This was after spending her childhood in disability institutions. Feeling abandoned by her parents and impacted by her experiences in institutions, Kim was left with traumas that tormented her for the rest of her life.

But Kim used what had happened to her to try to stop it happening to other people. She became a wonderful advocate and educator and made the world better for people with disabilities. She worked as an educator at the Intellectual Disability Rights Service for 20 years and she had major roles in Self Advocacy Sydney, NSW Council for Intellectual Disability, People with Disability

Australia, the Disability Council of NSW and Disability Advisory Council of Australia.

For three years, Kim represented Australia on a self advocacy committee of a world intellectual disability organisation that was then called the International League of Societies on Mental Handicap. Kim's committee told them to change their name to Inclusion International and they did. Because of that work, Kim was given the Rosemary Dybwad Award. This was an international self advocacy award that was only given each four years.

Through her work, Kim made many friends in the disability advocacy sector. Friendships that started at work became close personal friendships. Her closest friend was Faye Druett who led the support of Kim when she was dying far too young from cancer.

Kim's friendships included lots of talk about serious issues in disability advocacy but they

also included lots of fun. Kim had a great sense of humour and enjoyed “giving people a hard time” and receiving a hard time in return. When you were joking with her, she would pretend to be very cross and say, “Listen here mister!”

As an adult, Kim sought out her family. Her reconnection with her sister Lorraine, her father and finally her mother were all challenging experiences. She also found she had a half-sister who became a good friend.

In Kim’s advocacy, what she most wanted was for all the institutions to close so all people with disabilities could live full lives in the community. But it was really hard for Kim to talk about the institutions. They had hurt her so much. She sometimes steeled herself. She made a powerful podcast for the Shut In campaign which aimed to close all institutions.

All of us at NSW Council for Intellectual Disability were clear that the institutions were an outmoded system that needed to close. Kim was a particularly strong voice for this. She found it hard to see any improvements in the institutions over the years.

Kim's stance on the institutions was personal, principled and absolute. She refers in the book to a disagreement she had with some of us when the Integrated Services Project was being set up in NSW. This project aimed to meet the needs of people with complex challenging behaviour who were falling through the cracks between health and disability services and languishing in gaol, psychiatric hospitals and on the streets. NSW disability services proposed an intake unit as the first part of the project for some of its clients and that the unit be at a disability institution. NSW Council for Intellectual Disability strongly opposed the use of the institution but the

government was determined. Kim felt we should have fought harder to oppose this. We felt that we had done all we could without risking the whole project being delayed indefinitely. The unit went ahead at the institution. It was a failure, as Kim and we had predicted. To our relief, the government closed it down.

Kim wrote this book because she wanted it be read by politicians, senior bureaucrats and parents of people with disability. She wanted them to hear her story and heartache and make sure that what happened to her never happened to other people with disability.

The starting point for the book was conversations that Kim had with Cristina Ricci, with Cristina then putting the conversations in writing. Kathryn Knight then worked with Kim to further develop the text and put it into a form that was close to final and that Kim was happy with. Kim as usual chose her supporters


carefully. I think the final text shows that Kim chose well.

As Kim's executor, I have worked with Kathryn to bring the story to publication. We have had lots of valuable input from people Kim had said she wanted to comment on the text – Faye Druett, Jenny Klause, Cristina Ricci and Megan Scannell.

Kim led an extraordinary and harrowing life. Countless of us have benefited from her friendship. Society is that bit better for her example and relentless advocacy.

Jim Simpson
Senior Advocate
NSW Council for Intellectual Disability

Preface

im Walker was not only a rights advocate, speaker, educator and friend. She was also a storyteller.

Like all great storytellers, her heart was as wide as the desert plains, as deep as the sea, as high as the glittering stars, and sometimes as wild as the turbulent ocean that beat against the coastline where she was born.

It took Kim some time before she could tell this story. But when she was ready, she was fearless. She went to places that were difficult and dangerous for her. What carried her through was not only her determination, but her crazy, wicked and always infectious sense of humour.

I met Kim in 2004 when we worked together on accessible information projects. At forums and

consultations we introduced ourselves as “Kath and Kim”. It was an honour to play this double act with Kim, to be her friend, and like many others, to learn so much from her.

At the beginning of 2011, I offered to help with bringing Kim’s life story to realisation. Cristina Ricci had already spent many hours with Kim, and through perseverance and the trust they shared, the story was taking shape. I thought my background as a professional writer would be useful. I met with Kim often up till June. During this time, she always decided what she wanted to say, and when. Each time we met she would check through the writing from the previous session.

Whenever we reached a particularly difficult place, I would say, “Kim, are you sure you’re ready to go there?”

“Just write it down, Kathryn,” she would reply.

When Kim became ill, our work had to cease. She had enough on her mind without digging through her past. But when she was in hospital in Mullumbimby, she wanted to get this work finished. She was determined that her book would be published, even if she wouldn't be around to see it. She needed to know that her story would be told. I made her that promise.

Kim, I hope you are proud of this result.

Kathryn Knight



Kim & koala



Kim, Jacob & Shaz



"Get off your high horse and try to see it from the point of view of people in institutions – what it did to them and how it was hurtful for them."

1 Introduction

This is my story about my life.

When I was less than three years old, I was sent to live in an institution for children with an intellectual disability. This was a time, in the 1950s, when lots of children with a disability were sent away from their families to live in 'homes' run by the government. I grew up without knowing my parents or my brother and sister.

I was forgotten.



I am writing this story about my life now because I want everyone to know what life has been like for people like me. I want people to remember what happened to us, how we were

shut away and forgotten, and I want people never to forget this. I want people to understand what it is like for the people with a disability in this country who are still living in institutions. And I want to make sure that what happened to me will never happen to anyone again.

I don't blame parents for what happened to their children back then. I'm still trying to understand what things must have been like for those parents.

What I do know is that what their children went through – the abuse and neglect – was very, very wrong.

All people with a disability have the right to live in the community. All people, and that means people with high support needs too, have a right to make choices about their own lives, and to be loved and cared for. People with an

intellectual disability need to be part of the community, so that we can have the chance to learn how to behave the right way, learn how to work, and learn how to have relationships, just like everyone else.

Living in the community still might not be so great at the moment for a lot of people with an intellectual disability. But we all need to live together and learn from each other.



I've come a long way since I was in that institution. I've had to learn lots of skills for living independently and working. I've had to learn how to trust people. Trusting people is not easy if you've been locked away, and forgotten. You feel that no one gives a damn about you.

I've been found now.

I've lived in the community for many years. I've found friends and work colleagues, and I've learnt to trust them. I've done work that helps people with an intellectual disability to know their rights. And I found my sister, and my father and my mother. None of this has been easy for me.

I don't want anyone ever again to have a childhood like mine.

So, I'm asking you to try to see things in the eyes of people who have lived, and are still living, in institutions. Understand what it has done to them, and how bad it was for them. Try to put yourself into the world of someone with a disability -- get to know them. You might not be their friend, but if you can get to understand them better, you'll learn how to help them and make their life better.

Everyone has the right to enjoy their own life, and to celebrate who they are.

2 My early years



do not remember my childhood. I have very few memories from the time before I was 13 years old.

Most of the information here does not come from my memories, but from what people told me later, and what was written on my file.



I was born in Currie, in a public hospital in Tasmania on 22 November 1956. Currie is on King Island, an island near Tasmania.

When I was born, fathers weren't allowed to be at the birth of their children in hospital. My father got a phone call to say, "You've had a baby girl", and so he went to the hospital to



"I have one photo of me [as a child], taken when I was 18 months old."

see me. I was the first child of my mother and father.

Back then, my father worked in a mine, doing electronics work. Before that he worked on ships, then he was an electrician, climbing up poles and fixing wires; then he worked in a hospital, and then he worked selling tickets on buses. My father was German, and he had come to live in Australia in 1949.

My mother came from Scotland. She came to Australia with a friend when she was about 16. After I was born my mum worked as a nanny looking after a little boy and I used to play with him.

My father got another job, and we moved to Adelaide. My parents used to move around, about every 18 months. Fifteen months after I was born, my mother was pregnant with my brother. Because we didn't have anywhere to live then, we had to stay at a detention centre

for one night. Then we lived with a priest in his house. After that, my dad served beers and wine behind a counter in a pub, and we stayed there for a little while. It was then that the big problems began; my dad became an alcoholic, and he was running around with other women. My mum got very upset.

When my parents found out I couldn't talk, they tried to get help for me. But because they were migrants, they didn't know where to go or what to do. They took me to their doctor, who told them to take me to a specialist. I was taken to a couple of specialists, and they said, "She'll never be able to live independently, or have friends, or work, or socialise with people". These doctors told my parents that I would come to nothing. "Put her in an institution," they said, "and the people there will look after her."

My father took me to Watt Street in Newcastle. He signed the forms to put me in that institution on 8 August, 1959.

When he left me there, he did not go back to my mother. My mum was pregnant again with my sister, and he never saw any of us again. My sister, Lorraine, was born on Christmas Day, 1959. My mother tried to find out where my father was, to track him down, and she rang the priest who had helped them out. Of course, she was very angry.

My parents were told that they should not visit me in the institution, or try to contact me again. They were told that this would be best for me and for them.

I spent over ten years of my life at Watt Street.



I was very little when I was put into that institution. I felt very alone. I couldn't speak then, and so I could not express myself. No-one listened to me. As a result of my communication problems, I developed a lot of behaviour problems. No-one loved me or hugged me. I got punished a lot. I did not trust people: the people who looked after me came and went, and there was no-one who looked out for me.

I went to school inside that institution, with other children who had been left there.

I knew I had a mum and a dad, but I didn't know I had a brother or sister. I thought I was an only child. The first idea that I had that this could be wrong came at a school sports day. Once a year we had a sports day when our school went against other schools. One of these days is planted in my memory. I was about 13, and a teacher from another school

asked me, “Do you know a girl called Lorraine Pein?” I said I didn’t.

“I used to teach her,” the teacher said. “She’s in Stockton.”

At the time, I thought, “Ok”, but there was nothing I could do about following this then.

My mother came to visit me twice in all that time. I remember one time: I was eight, and my mother picked me up and took me to a café. I had a strawberry milkshake, and she brought colouring pencils and a book for me.

I don’t have an album of photos from my childhood. I have one photo, taken when I was 18 months old.

Instead, I have an institution file.




The Carriage Drive Insane Asylum Newcastle, 1888. Over the years it has been variously a "lunatic asylum", "hospital for the insane", and more recently, a psychiatric centre.

When Kim lived there during the 1950s and 1960s it was known as Watt Street Mental Hospital, an institution for "mentally defective" children.

Photograph by Ralph Snowball, Norm Barney Photographic Collection, Cultural Collections, Auchmuty Library, University of Newcastle. Reproduced with permission.

3 My years at Stockton

 went to live at Stockton when I was 13. The Watt Street institution was getting closed down, and the people with intellectual disability who lived there were being moved to other places. Watt Street was going to be made into a place only for people with mental illness.

Before I moved to Stockton, one school teacher and one other staff person took me there to have a look around. I got very upset then, and I remember holding onto the teacher's hand very tightly. I was frightened about the change, about what might happen to me. It's weird to think of that now, because I had not been happy at Watt Street. But it was somewhere I knew.

The teacher and the staff member showed me where I was going to live, in a unit for children with an intellectual disability who went to the school that was there in the grounds of the institution. This unit had children from six years old, as well as teenagers who were up to 18 or so years old. There were about 25 children in that unit, and it was divided into dormitories with six or eight beds in each one.



I was never told why we had to move to this new institution.

But I went to live there in January 1971. On that day, I was shown my bed in the dormitory. Later I was taken to the school with the other new children, and I met the teachers.

I was put in the OS class for children with special needs, and I stayed in this class for about two years. Then I went up a grade, and I

stayed in that next class until I was 19 years old. I was taught reading, writing, maths, sports, and cooking. I learnt other kinds of life skills, as well, like how to catch buses on my own.

It was there I also learnt how to stir people up!



When I had been at Stockton for a little while, I tried to find out more about my sister, Lorraine. I asked which dormitory she was in. I was told that yes, she had been here at Stockton, but she had already moved out. No-one seemed to be able to tell me where she had gone. It wasn't till more than ten years later that I finally met my sister.



The unit I was in had a rewards system, using tokens: you got a token if you made your bed properly, washed your hair, set the table, and so forth. You had a chart to keep track of your tokens, and if you got five tokens each day, then you got a reward at the end of the week, for example, an outing to the movies or the chance to buy something at the shop they had there. If you didn't get five tokens a day, you did not get a reward, so you had to try your hardest to get these tokens.

You had to learn very quickly how to get around the staff: to be polite, not answer back, things like that. When you were naughty, they punished you. You were punished if you made a mess or spilled your drink.

The staff would often hit the children, or they would get the other kids to laugh at you if you made a mistake.

If you were really bad, you were strapped into a high chair, then the chair was laid down and you were hosed with the hose. I was only put into the high chair once.

Other things that happened were that people threw buckets of water over you to wake you up, or they made you stand in a corner and would not let you eat your breakfast. Often you were given cold food, or you got the same food for breakfast, lunch and dinner. When that happened, I threw the food out. Treatment like this is abuse. Because of this treatment, trusting people has been very hard for me.

In all that time, I never hurt another person on purpose.



There was one staff person we hated the most. We said she was like Hitler (even though we didn't really know who Hitler was). She had a

motorbike, and because she used to give us a hard time, we would flatten her tyres. Then she lined us up and walked down the line, stopping at each person, and staring. “Did you do it?” she would ask. When she got to me, I owned up and said, “Yes”. Of course I got punished.

I’m not saying that all the staff there were bad. There were some good people, and some went out of their way for us. Like one staff member who helped us get a dog. We were on an outing to the vineyards one day, and we saw a lovely cocker spaniel, and they told us that he was going to be put down. We asked if we could keep him, and this staff member said that we could. So the dog came home with us.

We taught our dog how to knock on the doors of the classroom when we were at school, and sometimes he came on excursions with us. I remember that one day we sneaked him onto the bus, and hid him for most of the trip. When

we were about to get out of the bus, the teacher found out that the dog was there.

“Who put Rusty on the bus?” she asked.

“We don’t know,” we said. “He must have got on by himself.”

Rusty was old when we got him, but he lived with us for six or so years. We really loved that old dog.

When children grow up in institutions like Watt Street and Stockton, they never feel like they belong anywhere. They never get hugged, and they are not loved. You feel like you are not a person. You are just one of the numbers.

You don’t feel like a whole person. You are just someone to be looked after, and then moved along to the next person, and then the next. You are not a child, only a part of the system.

An institution is not a place for anyone.



Not Rusty, but another canine friend

4 Finding independence



A group home or hostel was set up in Newcastle, and it was run by parents of children with intellectual disability who had been in institutions or who had left home. This group home was set up to teach people with an intellectual disability how to live with other people, socialise, cook, clean, and share duties. About 20 people lived in that house, so you could say it was really another institution. It used to be a boarding school.

Just because it was called a “house” doesn’t mean it wasn’t an institution.

On the very first day I went to the hostel, I went back to Stockton. I escaped back to the institution for a couple of hours, because my friends were still there, and because I knew

what it was like there. To me then, Stockton was a safe environment, and the only place I knew. At that time, I didn't know anything different.

At this hostel, two house parents stayed there and were paid by the parent group to look after the 20 people with an intellectual disability who were living there. Their job was to teach the residents how to shop, cook, clean, and keep their room tidy. Their job was also to be there if anything happened. They were like a mother and father figure to us. They had their own flat, and they had two children of their own. We would babysit their children sometimes.

We all had our own rooms there, so it was very different from the dormitories at the institutions. Some rooms were big, and some small. There were some good times there, and some not so good times too. We had some fun, but sometimes we got punished, and sometimes we weren't allowed to have food – if we were

naughty, or we back chatted or our room wasn't tidy. I didn't know then that this was against the law. Sometimes we went on outings: to the movies, on picnics, to see friends, or to take the house parents' children swimming. Some of the people who lived there could go home on weekends to see their parents, and go home for Christmas. I had to stay at the hostel then because I had nowhere else to go.



I lived in this group home for about five years. At first it was scary, because you had to do everything by yourself. You had to get up in the morning, feed yourself, get ready for work, and you had to get on with different people. At Stockton, everything was done for you.



Kim, on her 21st birthday

I stayed where I did for so long not because I wanted to, but because I didn't know anything else. Like learning to swim, you only go up to the point where you feel safe – and for me, that was living in an institution. Until I was shown that life could be different, I didn't know anything else.

Until I was shown that life could be different, I didn't know. Now, with what I know, I would put a bomb under all institutions.



The deal was that if you lived at the hostel, you had to go to work. So everyone who lived there went to work, either at a sheltered workshop that wasn't far from the house, or at another place that people had to travel to. I worked at Stockton in the laundry. I travelled back there every day. I put sheets through a

"I went to another workshop. It was longer hours. I used to cross off some writing on the labels. I got very bored.

"You worked on a bonus system again. It was better pay. My hands were affected by my epilepsy when I was younger and they couldn't work as fast as other people's. I used to get \$25 a week. That was good though.

"Then I went to another sheltered workshop with a laundry, I fed the sheets through. I got about \$15 per fortnight.

"It wasn't very good. So I left there."



(From I Always Wanted to be a Tap Dancer, pp 93-4)

machine to iron them and got paid not much for full time work.

After that job, I looked after the house parents' little boy, who was two years old. I worked with him until he was four and a half, and it was like working in open employment.

Then a friend of the house mother, who was a hairdresser, asked her if she knew anyone who did babysitting, and could babysit her son. The house mother talked to me about it, and we had a trial run, on the condition that the house parent would be around just in case something happened (but nothing ever did). I liked this job, and found it very hard and very demanding. I had to find things to do with the little boy, like play on the swings and go to the park.

Finally, I moved into a flat that was attached to the hostel. They put me together with another girl. We got along very well to begin



A new job in open employment

with. We did not have support staff with us then, and we had to look after ourselves like everyone in society. My flatmate also had an intellectual disability, and she worked at the same place as me.



By this time I had a different job, working in a sheltered workshop in Hamilton, and we packed chickens. A truck delivered chickens to the factory, and we packed them up in boxes. It was a cold area; we had to wear long clothes, boots and gloves, and because we were handling food, we had to be very clean. I had very long hair then, and I had to put it up in a bun and wear a hair net. My job was to put blotters on top of the little plastic trays that came along the conveyor belt. This was to stop the blood from the chickens running through the trays. One person put the tray on to the

conveyor belt, one person put down the blotter (that was me), another person put a chicken on top of the blotter, then someone else packed the chicken into a box.

We had to stand up all day in the cold. We took our lunch with us -- we could order it, but it cost too much to do that.

I did this for more than two years. Most of the people working there had an intellectual disability, and some had mental health problems. I got paid \$8 or \$9 a week on top of my pension – for full-time work. I didn't know anything about rights back then.



Later, after I got my first job in advocacy, I moved out of the hostel, and into a flat by myself in Hamilton.

Living alone was very hard in the beginning; I got lonely, and I had to learn how to find my own friends.

I also had to learn how to pay my rent and things like that, as I didn't have a community worker then. I didn't have any support around me. But that's the way I wanted it – all my life I had lived with people with an intellectual disability, and it was time to cut the cord.

I knew I was an independent person, and I felt I had to prove I could do it, to the people who work with people with an intellectual disability, to the community, to my parents, and to myself. I lived on my own for a couple of years. But I got sick of living on my own, and so I ended up sharing with other people in a couple of other places around Newcastle.

Then I made my biggest move. This was when I had to go to Sydney, for my new job with IDRS.

But I had a lot of questions to find answers for first: Where would I live? How much would the rent be?

I went to a real estate agency first, and they helped me read the paperwork, and they took me to see some places. I got a place to rent through them, but it was very expensive. Then people at IDRS helped me fill in the forms and apply to get a DoH flat in Sydney. I had to wait for a while for this to happen. But I needed some more help, to show DoH that I needed rental assistance. The people at Redfern Legal Centre took my case up, to help me get crisis housing.

Finally, I was in my own place in Redfern, where I lived for many years.



So my journey has been from being placed in an institution, to living in a group home where there was support from staff, to sharing a flat with another person with a disability without support, to living by myself independently.

These steps made it easy for me to finally live by myself, but it took a long time. This process was not easy. I have learnt to live by myself. I have learnt from my work at IDRS that people need space, and I have also learnt that I can be happy to come home, and be myself, and have my own space.



The community is not an easy place to live in.

If you've been shut away you don't know how to act or how to be part of the community. You

haven't learnt how to behave, or how to set boundaries. Some people from institutions behave in ways that are not right in the community. They might just come up and hug someone they don't know well, and they don't know that that is not what people do.

For example, when my sister Lorraine came out of the institution, I wanted to make sure that she could interact in the community. Every week I took her to the RSL club, with her carer, for dinner. Once or twice she got upset because she didn't understand that all the drinks on the tables were not hers. Once she took a little girl's drink and the little girl got upset. I explained to her mum that Lorraine did not mean to do this, and I bought a new drink for the little girl. But then the hotel management came up and asked us to leave because Lorraine was disturbing other people.

Because people in institutions don't know how to behave in the community, people can take

them the wrong way, and say they're 'whacko'. Unless people in the community have had something to do with people with a disability in their lives, they don't understand. It's a bit different today because people with a disability are everywhere now.

When I came out of the institution, there were not as many people with a disability in the community, or as many services for them as there are now. The community in those days didn't know about group homes, or 24-hour support, or community educators.

Back then, the community needed to learn that people with an intellectual disability were just the same as everyone else.

They just needed some help, and some training in how to be part of a community.

The community still needs to be educated about the rights of people with an intellectual disability. Some people, including some

parents, still feel that it's okay to keep people with an intellectual disability and complex needs locked up in an institution. We – the people who have got out and made our lives work outside the institution -- need to educate parents and the community. We need to work together, so that our society helps children with an intellectual disability, their parents, and their families.



"We all have to work together so that people with an intellectual disability can live in the community, and get the help they need, even if they have high support needs."



Kim-isms

It's very complex
for me

**Yes,
mate!**

Close
all institutions!

Yeah, yeah, yeah,
all right

**People with
intellectual disability
should be there
from the start**

**It's got to
be in
easy read!**

And so on and so forth
and things like that ...

Got to give you a
hard time!

**What about
people with high
support needs?**

5 Finding my voice



ow I got into the disability sector was a fluke!

I was living in a flat at that time, after I had moved out of the hostel. Jan, a woman who worked at the disability department, was teaching people with intellectual disability (including me) skills for living in the community – shopping, cleaning, using transport, handling money, personal hygiene, and so forth. Jan went to a conference in Queensland where she saw a presentation on setting up self advocacy for people with an intellectual disability. She was interested in setting up something like that in Newcastle, so she organised a meeting and invited people with intellectual disability from

the community and from the hostel where I had lived. I didn't really want to get involved then, but one thing happened that made sure I went to that meeting.

Jan told us that the presenters from the Queensland conference were coming up from Sydney to talk to us. Then she told me who the presenters were: one of them was Robert – my very good friend from Stockton. I had not heard from him for many years, and I really wanted to see him and find out how he was going. That was the real reason I went along to that meeting.

More than 30 people came to that meeting. Robert was there with a guy called David. They showed us a film about learning to live independently when you got out of an institution, about standing up for yourself. They told us about Self Advocacy NSW, and how it worked. I saw Robert before the meeting.

“Here comes trouble,” he said when he saw me.

We had a good chat.

My first job in advocacy

After that, Jan organised another meeting with about eight people, to talk about how we could get funding from the disability department to set up our own self advocacy group. Then we tried to get some money, but we were not successful. It was too soon – we didn’t have the skills, and we needed more training. We waited for a while, until we got more training, and until we worked out what we wanted to do and what we wanted the money for. We had to use some of our own money to help pay for the training. But it worked. We put in another submission, and we were successful.



The girl at the centre...

We got funded, we got an office, and we got money to hire three people. One of the jobs was for a community communications worker, for two days a week. It was a job especially for a person with an intellectual disability. There were two parts to this job: firstly, to help people with intellectual disability learn about self advocacy; and secondly, to do forums – to go around talking to governments and professional people about self advocacy. Jan and I talked about who would be the best person for this job.

Jan thought I could do it.

She saw something inside me that hadn't come out yet.

But I felt that there were others who could communicate with people better than I could. I was afraid. I was worried that when I got up to talk, the people I was speaking to – doctors, nurses, service providers – wouldn't

understand, they wouldn't believe that people with intellectual disability could do the things I was talking about, like standing up for ourselves. I told Jan that I would put myself forward, I would apply for the job, but if someone else wanted it, I'd let them have it. I'm not good at taking compliments.

In the end, I got that job! I was very excited about it. I was working with two other people: a community worker, and an office manager (a paid person who looked after the money, and so forth). Jan was our advisor; she explained the funding guidelines, and what our responsibilities were. The community worker job was full-time. The person who got that job seemed good at first, but when we got to know her, we changed our minds. She treated us like children.

Part of my job was to show the staff about how to work with people with an intellectual disability in self advocacy and speaking up. I

also had to go to conferences and do presentations and give papers about how we set up self advocacy groups and how we included people with an intellectual disability.

I never worked in a sheltered workshop again.

Becoming a public speaker

Pretty soon I had to go to a conference in Queensland with Jan, to speak about setting up self advocacy in the Hunter. I was very nervous, and felt quite sick. I had never been on a plane before, and I had never spoken in front of people at a conference. Jan had to comfort me, and calm me down. But I went ahead. I got very scared, I stumbled over my words. It wasn't easy, but I did it. We stayed in a camping ground and slept on bunks at that conference.

There were other trips, too. Not long after the Queensland conference I went to Adelaide for ten days with the people from Self Advocacy Sydney, to learn about self advocacy in other states.

Once I got involved with self advocacy, I learned to shine.

Jan thought I was a very good public speaker, but I still needed more training. With our funding we paid for a trainer to give us training over four weekends to the people involved in our Self Advocacy Hunter group. The trainer taught us listening and public speaking skills, and building self-esteem, as well as things like dressing properly, making eye contact and understanding personal space. She videotaped us when we were doing role plays. Then someone from Toastmasters came to speak with us, and after that we had some more training with that person, over about two months.

My introduction to IDRS

As part of my job, I went to a self advocacy conference at Valet Park, near Lismore, and there I met a person called Pam from IDRS. Pam was interested in setting up a “Rights Forum”. She said the forum would be a group of six people with intellectual disability who would advise IDRS staff of what the issues around rights were for people with intellectual disability and how their staff could support them in the best way. She asked me if I wanted to be one of the six people on the forum. I said no in the beginning.

I didn’t want to always have the ‘intellectual disability’ label, and I didn’t want to always work with people with a disability.

But then I changed my mind. I joined the forum, and the six of us met once a month to talk about issues that were important to us.



"We were the teachers."

The IDRS people showed us a video – it was an educational video that used puppets to teach us about our rights. We asked them why they used puppets. We told them that we were not children. After all, the video was to tell people about rights, and what rights are – not to show people with an intellectual disability as children. They understood this, and from then on, we always worked with IDRS staff and helped them with the documents they were working on (like letters, policies and resources), to put the words in a way that people with an intellectual disability could understand.

The staff used to bring along all their documents once a month for our comments. I was on that rights forum for a term of four years, then a new group of people took over.



*At the launch of the
"Rights at Work" kit in 1987*

Then IDRS wanted two people to work with one of their staff members, to travel around NSW talking about a kit that was for people working in sheltered workshops (now called business services). They wanted to find out if people with an intellectual disability could teach people working in the business services about their rights. The project was funded for

six months. I was one of the two people who got this job, and we went around NSW with Jenny, the IDRS staff member, to talk about this kit. We talked about pay, about rights as an employee (things like leave and work contracts), and about how to get more involved by getting onto Boards.

The answer was “yes” – we could teach people about their rights.

Because we did such a good job, the project went on for three more months, and then for six more months.

Because it worked out so well, IDRS thought: if this is the best way to work with people with an intellectual disability, then they should have a permanent job for someone to work one day a week at their legal centre for people with an intellectual disability.

All this time I was still with Self Advocacy Hunter. Someone had been filling in for me

there while I did the IDRS project. So when the new job came up at IDRS, I had to think about what was most important: to stay at Self Advocacy or to go to Sydney to learn more about rights. I wanted to stay involved with Self Advocacy, but I loved doing that job with IDRS. So I applied for that job. Other people were going for it too. I went for the interview, and I was the successful person. So, after working with Self Advocacy Hunter for six years, I left. But I kept up my involvement with self advocacy, and was on the Board of Self Advocacy Sydney for the next 14 years.

6 Finding respect

I was still very shy when I started the job in Sydney at IDRS. The staff there taught me so much. When I first started there I was still living in Newcastle, so for my new job in Sydney, six hours per week, I had to travel two hours each way. I did this for two years - it was really crazy!

Then it was time for me to make the big move. I had to go through the process of applying for a DoH flat in Sydney, and waiting, and finding myself in a new place that I didn't know. But I managed to get through all this.

I loved my new job at IDRS and over the years I did a lot of rights training for people with intellectual disability.

The people at IDRS were the very first people I learned to trust. I didn't really trust anyone

before then. Growing up in institutions, I learnt how to act and not to act with people, and if I did or said anything wrong, or anything that they didn't like, I got punished.

So for me, trusting people, even to this day, is not easy – it takes me a long while to get to know people, and to trust them.

I trusted the people at IDRS because they took the time to help me understand that people who did not have an intellectual disability actually could be nice people! They took me under their wings – I didn't know what to do, how to do it and how to start my first steps in trusting people. And so they showed me the ropes and taught me how to ask questions, how to work beside people, and how to build relationships. They were the first people in my life (outside the institution) that I ever got close to, and they probably always will be part of my life.

On the international stage

In 1993 I got the chance to work on an international project with the UN. That was fantastic.

The UN got a person called a Special Rapporteur to set up a sub-committee to look at the rights of people with an intellectual disability, to look at where different countries were at with their self advocacy programs. That person (who was from Sweden) sent a letter to the Australian Government, who sent it on to NCID. They wanted someone from Australia to be on their committee. I got that job! I was chosen because by then I was a very good public speaker.

What happened was that we had four trips overseas in the next two years. Jenny from IDRS helped with organising the meetings and the travel, and she came with me to support

me. The first trip was to Amsterdam for a committee meeting. There were six people including me, and the others came from New Zealand, Canada, Holland, Britain and Sweden. I got along very well with them all, but the highlight was meeting Oker, the person from Sweden. He was tall and thin, with white hair. He didn't speak English, so we had to speak through an interpreter. He was a beautiful person, and I felt lit up whenever he was around. At the committee we talked about self advocacy in our own countries and what we could do for people in poor countries. We had to make a plan of what we were going to do, and send this to Sweden. We decided that we would put together a booklet on self advocacy.

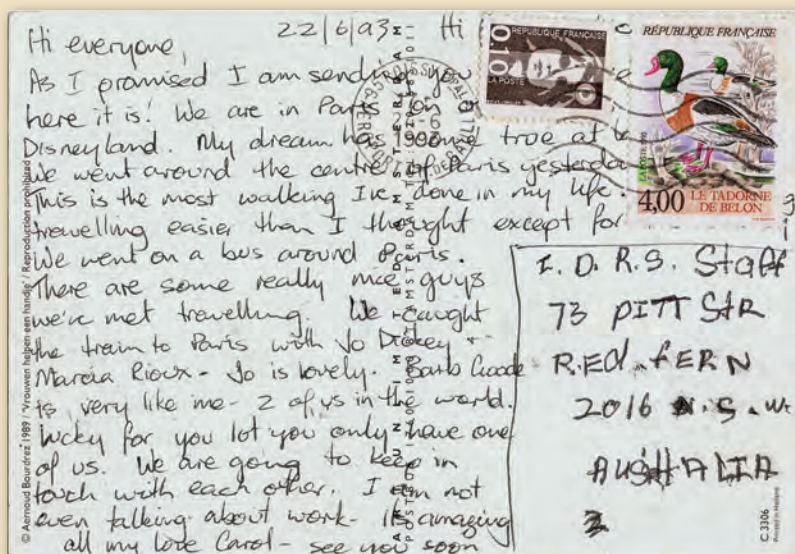
Six months later Jenny and I went to Toronto in Canada, to a Self Advocacy Conference. The other people on the sub-committee and I talked about our project. There were some inter-

national people there, but most were from the US. Some people from self advocacy in Australia were there too, and we all went on a tour around Canada afterwards.

Then we went to London for another meeting of the sub-committee. Just before that meeting, I went to Vancouver in Canada to spend a few days with my friend, Barb, who was on the sub-committee.

**In London we brainstormed the big issues.
My big issue was getting people with a
disability out of institutions.**

People with a disability were still in institutions in Britain, Canada and Australia, but not in Holland, Sweden and New Zealand. We worked on our book, called *Beliefs and Values*, and I had to report to NCID about what went on at the meetings, and what was going into the book about self advocacy in Australia.



Postcard from Paris. 22 June 1993



"At the UN committee we talked about self advocacy in our own countries and hat we could do for people in poor countries."



*Members of the UN Self Advocacy Subcommittee, 1992-1994
(Kim, second from right)*

The last trip for the project was to Delhi in India, for the Inclusion International Conference (that was the new name that we gave the international conference on disability that was put on every two years). I worked very hard with the people on my sub-committee to get people with an intellectual disability involved in the Conference for the first time. There were two parts to the Conference, one for people with an intellectual disability, and one for people without. We ran a lot of workshops for people with an intellectual disability. Also, our book was finished in time for that Conference.

The story that I wrote in that book made Australia look a long way behind other countries in the way it treated people with an intellectual disability.

I made some very good friends while the project was going on. Jenny and I had to write up a big report for NCID, with

recommendations, a job that took a long time.
That was the end of the project for us.

More experience working in advocacy

All in all, I worked at IDRS for 17 years and 3 months, but really it was 20 years if you put in the first project, with the business services kit. After three years there, I got an extra day's work. So as well as my education role, I started to travel around with an IDRS trainer to teach people from the disability department about working with people with an intellectual disability on issues like accommodation, guardianship, relationships, work, advocacy, and abuse.

I did other things too in that time. Sally from IDRS asked me if I would like to get involved with a group called SORO (Speak Out Reach Out) that was set up by CID. The aim of SORO



With friends and colleagues at IDRS



On the phone – as usual!

was to put information into formats that people with intellectual disability, service providers and parents could understand.

Around this time, a place on the Board of CID came up, and I was asked to go on.

I wasn't sure if I could do this; there were only two people with an intellectual disability on the Board, and there wasn't any real support for us then. But I agreed to do it, and I was on the Board for about five years. Things have changed since then: there are now more Board members with an intellectual disability, and more support for them. Since 2006, when the Constitution changed, eight people with intellectual disability have been on the Board. Now a participation worker is employed to support them.

I also did other work in the disability sector. I worked on accessible information projects for DSARI and PWD. My friend Sally was at

DSaRI, and she asked me if I wanted to work on their accessible information projects. This was like the work I had done at IDRS, when I helped to put the words on their resources in a way that people with an intellectual disability could understand.

I also spoke at forums and ran focus groups that gave people with an intellectual disability a chance to say what they thought and what they wanted in their lives.



So over the years, I've been on lots of committees – too many to mention here, and I've worked on many, many projects. I loved doing that work, and I was treated with respect by many different people.

But in 2006, a lot of things were going on for me. I decided that I could not work in the disability sector any longer.

But first I need to talk about some very important people who had come into my life.



Kim with friends from the Women's Group she set up



Kim and fellow CID Board member Michael Herdman meet with Productivity Commissioner Patricia Scott

7 Two important people come into my life

When I was in my mid 20s, and living in the group home in Newcastle, I went back to Stockton because I wanted to look at my file. But I was told that the file was Stockton's property, so I couldn't have it. While I was there I asked the superintendent if I could find out where my sister Lorraine was.

From the time I was 14, I knew that I had a sister but I never knew where she was.

The superintendent looked into this for me, and he found out that Lorraine was living at Rydalmere Hospital, an institution for people with an intellectual disability. He wrote me a

letter telling me that they had found her, and asking me if I would like to meet her. I had to think about that. I didn't know if I wanted to go back to any institution, and I didn't know how I could get there, as I was living at the hostel in Newcastle then.

I had always known that my sister had a disability, but it was a shock to me to find out that she was living in that institution.

The superintendent rang me, and then he talked to the social worker at Rydalmere Hospital. The social worker phoned me, and she told me about Lorraine's disability. She said, "Lorraine can talk, but her disability is a severe disability". Then she asked me if I wanted to meet Lorraine. This was a lot for me to take in, and I said I needed more time to think about it. After a couple of weeks I rang her back, to tell her I had made up my mind, and I wanted to see my sister. This social worker organised a visit, and the house parent

at the hostel drove me down to Sydney. The social worker met us out the front and took us to Lorraine's unit.

Meeting Lorraine

When I saw Lorraine, I got biggest shock of my life. I had not realised that her support needs were so high. She could walk, but her intellectual disability was severe, and I didn't know if she understood who I was. Anyway, the social worker took us out for a meal to a Chinese restaurant. Lorraine was okay, but she ate very quickly with her spoon. I couldn't help thinking, how could this be my sister? I spent about three hours with her, then I stayed overnight in a motel. The next day the house parent and I went back to Newcastle, and I was thinking all the time, no, my sister can't be like that.

I kept thinking, I don't want a sister who is damaged or broken; I want a sister who I can talk to, and interact with, and laugh with, and do all the things sisters do together.

After that first visit, I rang the hospital a couple of times to see how she was going. When I left the hostel and was living in my own flat, I went down to Sydney three or four times to visit her. Each time I stayed for ten to fifteen minutes. We sat on opposite sides of the visitors' room. I didn't talk to her, I just watched her. I'm still not sure if she knew who I was.

A few years passed like this and then I started being with her for longer and talking to her more. But there was still something there that stopped me getting close to her. It was probably because of where she was – in an institution – and how this place looked and

smelt, more than how Lorraine looked and how she spoke.

It took me a couple of years before I really understood how much Lorraine meant to me.

That came after a time that was very hard for me.

Meeting Faye

I met Faye back in 1984 or 1985.

Some people wanted to put together a book about the lives of women with disabilities. They got some money from the government to do this. Faye was on the Steering Committee for this project. She was trying to find twelve women with different disabilities, and someone gave her my name. She came to meet me at

IDRS and told me what she was doing and why they were doing the book.

I had to think about whether I wanted to get involved. In the end I decided to try it, and I met a couple of times with her, then someone else did the interviewing. The book that came out of this was called ***I Always Wanted to be a Tap Dancer***.

That's how I met Faye. There were women who had cerebral palsy, psychiatric disability, physical disability, intellectual disability, and who were blind and deaf. They got together to talk about what should be in the book.

When Faye spoke to me then, she used a big word that I didn't understand. I said to her, 'Why did you use that word that I can't understand?' She said, 'Oops!', and told me she didn't know how to put it into simpler language. I told her that people with an intellectual disability should be treated like

everyone else, that people should make the effort to include us.

We became friends through that book.

In 1996 I had my fortieth birthday party at Faye's place. That was when Faye was still living in Sydney. My actual birthday was the day before the party, and Faye and I went to visit Lorraine. That was the first time Faye met Lorraine. We took some food with us, and went outside into the garden. Straight away Lorraine went over to Faye and said, 'Mummy, mummy.' Lorraine still calls Faye 'Mummy', and Faye thinks that is fantastic!

My birthday party was a big one, with about 40 people. We went to get Lorraine from the institution early, before the party started, so she could get used to the place, and she had a really good time.

Hospital crisis

In 1997, Lorraine had a bad accident. I found out later that as well as her intellectual disability, Lorraine has a mental illness (bipolar disorder). She also has a medical condition that means she can't stop drinking fluids. So when she drinks water, her brain doesn't tell her when to stop.

This time she had way too much water to drink. This made her go unconscious. They found her on the floor in her room, next to her bed. I got a phone call from a nurse at the institution.

She said to me, “You have sister called Lorraine Pein, and she is in Westmead Hospital, unconscious.”

I asked what happened, and the nurse said she didn't know. They didn't know about her medical condition then.

I had to ring around to see if I could get someone to help me deal with Westmead Hospital. I phoned Faye, and told her what had happened, and said I needed someone to take me to the hospital. Faye's friend, Chris, explained to me what "unconscious" meant, as well as "intensive care" and being "in a coma".

Lorraine was in intensive care for ten days. I was crying when we got there and I screamed when I saw her lying there with tubes coming out of her body everywhere. Chris and Faye asked if I wanted to stay with them for a while. I said yes (I was still living in Newcastle then), and I called both my workplaces (I was doing two jobs at this time) and asked them for leave. I went to the hospital every day, and twice I tried to sit beside her bed, but I got too upset in there. So I used to sit just outside her door. Chris and Faye went in to see her, and they tried to take me into her room, but the sight of all those tubes was too much for me.

Once when I was there, the social worker said to me, “This is not *Home and Away*, you know; this is real”.

“Don’t ever speak to me like that again,” I said. I wanted to punch her.

Then the old superintendent from the Rydalmere institution came to the hospital to see Lorraine. I told him to “F@+#! off!” I was so angry because I felt that they should have known about her medical condition. If they knew, then maybe she wouldn’t have got that sick.

“Don’t ever say that again,” Faye said to me.

Lorraine stayed in hospital for two months. Whenever anyone from Rydalmere came, I swore at them – I couldn’t help myself. We had to have a lot of meetings with them, and I kept telling them not to come near her. I was in shock more than anything.

Faye and I talked about what would happen to Lorraine, and who would be responsible for her care and support. Faye said that she should be her advocate for medical treatment, and that Faye and me could be her joint advocates for any other things. We met at least once a week to work out how to keep Lorraine safe. .

We did this for six months, but it really didn't work out. I was so emotionally upset that I didn't listen well, and so I had a support person to help me. But I started to fight with Faye, and that was mainly because some of the issues happening for Lorraine touched a raw nerve for me, and made me angry and confused. Faye suggested that she became the sole advocate. I said to her, "You do what you like, lady". I was very cranky about it then, but I understand it all better now.

There were many problems with Lorraine's behaviour, like getting up at night and screaming. They wanted to give her drugs, and I just couldn't handle that.

Over this whole period of time I became closer to Lorraine, and I realised how special she had become to me. Faye is still Lorraine's advocate.

Bringing Lorraine into the community

Once Faye knew about Lorraine living in an institution, she wanted us to talk to Faye Lo Po, who was the NSW Minister for Disability Services, about getting Lorraine out of there. We wrote letters, and we got a letter back from

Faye Lo Po saying, “I’m looking into it”. Then we wrote a stronger letter.

Faye Lo Po went to meet Lorraine. She asked us, “Why is she in this institution?”

I told her some of the things about my past, and how my parents had separated when we were very young. That started the process of getting Lorraine into a group home, but it took a couple of years to finally happen.

When Lorraine came out of the institution, she moved into a group home for people with low support needs. Faye and I wanted her to go into a house where people could communicate with her, and interact with her. One day, after I had visited her, she came to door with me to say good-bye, and she shut the door nearly on my face. I admit I thought then that I’d had enough.

Lorraine stayed in that house for a couple of months. She got on well to begin with, but we think that after a while she felt that there were things she wanted to do herself. These were not things that were good for the house. One day she went to the fridge and pulled out all the food, and made a big mess. She used to get up in the middle of the night and make a lot of noise.

After a meeting, they decided that she should be moved to a place in Bondi Junction that was really a small institution. There were only four people living there, but it looked and smelt and felt like an institution. I got very upset when I first saw it, but then I settled down and realised that this would probably be a better place for her, as the other residents had higher support needs like her. Then this place closed down, and Lorraine was moved, along with the other residents of that house, to another group home. There are some problems there, but the

staff are fantastic with her, and she relates well to them.

My relationship with Lorraine now is very different. Now I don't see her as someone who looks different and can't do things. But I was shocked back then. Back then I didn't really look at Lorraine as my sister. I saw her as part of the same system, that she had the same mother as me, but that was it.

But now I see that she has taught me some important lessons, that people with very complex needs like hers can have a quality life, and have a right to be included in the community.

I don't think I understood that before.

Some people just need different resources to help them move into the community and to interact with people.


I love my sister. Lorraine is my best friend.

As for Faye, she has always been there for me: when I was going through the hard times with my parents, and so forth, and then later, when I got sick.

When Faye was not well for a time in the late 1990s, I was devastated. I thought that she wouldn't be around for long. She said that if anything was going to happen to her, she would let me know. But I didn't want anything to happen to her; I didn't want her to leave me.

I know that Faye really does love me. I am so grateful to her.

8 My parents come into my life

 tried to get in contact with my mother a couple of times in the 1980s and the early 1990s. In 1998 I decided to try to contact her again.

I got my mother's address through a friend of a friend who worked at the electoral office. I wrote a letter to her, telling her that I was looking for her. It was not a friendly letter. In it I asked: Why did you give me up? Why did you put me in an institution? She wrote back, saying that my letter had made her angry and upset. She felt I was putting all the blame on her; she couldn't talk about it, it was all too painful.

I wrote back to her. Then she wrote to me again, asking me not to write back.

I found out through that letter that I have a half-sister, and I went off my rocker. I was so angry that she had kept my half-sister and not me.

That's when I started to hate all parents who had a child with an intellectual disability and put them in an institution. She chose that child over me.

Years later, when I finally met Karen and my niece and nephew, I was polite to her, but I said, "Why did our mother choose you over me?"

Karen said, "I can't answer that. You'll have to ask her."

Karen knew nothing about me or our sister Lorraine until 2004.

Changing my name

In 1999, I started to think about changing my name.

I didn't have anything to do with my parents, and they didn't want anything to do with me. I wanted to get free of them, and be who I wanted to be.

I rang DOCS to see if I was ever made a ward of the state. I did this because it's harder to change your name if you are a state ward. I also asked if Lorraine and my brother were wards of the state. DOCS told me that they couldn't give me this information, and said I should talk to an adoption agency in Parramatta. A woman put me in touch with this agency, so I rang them.

The people at the agency told me about how they helped people find their families. We talked about what I wanted to find out: if I was

made a ward of the state. DOCS wouldn't tell me, but the agency was able to get this information. I thought it was strange that DOCS would not tell me, but they would tell an agency.

It took a while, as there were a lot of processes to go through. The agency rang back to say, "We have your records, but there's not much about you in them. There is more about your sister and brother." They told me that I was never made a ward of the state, but my sister and brother were. They did not tell me why, and they would not give me any more information about Lorraine or my brother. They said that didn't have anything to do with me, and I thought that was fair enough. They had no record of my parents, and they didn't even know if they were alive or not.

In my file it said that I was only going to be at Watt Street, at that institution, for a holiday. That was a bloody long holiday, I thought.

So now I had to think about what I needed to do, how to do it, and where I needed to go next. One afternoon while I was in the bath, I decided that I would change my name. My parents never tried to find me, so why should I worry about finding them? Why should I still have their name?

So I was thinking in the bath, "What am I going to call myself, and how am I going to be happy again? How can I be sure this will make a difference to me?" So I talked to a couple of people about changing my name and so forth. They said to me, "You can call yourself whatever you want to call yourself, but you will always be Carol to us."

I liked a show called *The Walker*, a show about a sheriff. So I thought, I like the name “Walker”, I don’t want the name “Pein” any more. My parents had no right to make me use that name any more, and I didn’t think of myself as a Pein any longer.

So I decided to call myself “Kim Walker”. I got someone to help me to go to the office of births, deaths and marriages to change my name.

I was going to become *Kim Marie Walker*, because I liked that name.

Something happened then that stopped me from filling in those forms, and going through with the paperwork. But I’ve been known to my friends and in my work as “Kim Walker” ever since.

Finding my Dad

My dad came into my life two days after the phone call to DOCS, after I had started filling out the forms for changing my name. It was Sunday, March 23 at 6.30pm, and I was watching *The Nanny* on TV when the phone rang.

There was a man's voice, asking me if I knew someone named Robert Hans Pein. I asked, "How do you spell the last name?" It was the same spelling as mine. Robert was my brother, and on the phone was my dad, ringing me from Germany where he now lived, looking for my brother.

"Did you have any other children?" I asked him.

"Yes," he answered, "two girls."

"What are their names?" I asked.

“One is called Carol and the other is called Lorraine,” he said.

“Where were your daughters born?”

“My oldest daughter was born in Tasmania, on King Island.”

Then I asked, “How do you spell the last name again? Do you spell it p-e-i-n?”

“Yes,” he said.

“I’m not sure,” I said, “but I think you might be speaking to your oldest daughter.”

He asked me about myself, and we spoke on the phone for about an hour. I couldn’t help worrying, though, that someone was playing a joke on me.

He rang again a couple of days later.

But I pushed him away: I wanted him to work hard, to earn the right to get to know me.

Two or three days after that, he rang again. I listened; I didn't speak much; I didn't give too much of myself away. When he said good-bye, I just hung up.

We stayed in contact by phone for about a year. When he knew that I felt comfortable with him, after twelve months, he asked if I could tell him where my mother was. Of course I knew where she was, because I had been in contact with her. I told him what she had written to me, that she just wanted to put the past behind her and get on with her life. But I would not give him her address.

If I seem hard on him, remember that he is now talking with his daughter who he took to an institution, his daughter who was never going to be able to speak. He told me that it was him who took me to Watt Street when I was two and a half years old. He took me there and then he went away and never went back to my mother. He said now he just wanted to get

to know his family again. He said that he thought Lorraine and I might still be in an institution, and that he didn't think he would ever be able to find us. I thought that because he was getting older, he wanted to contact his family in Australia and get some closure before he died.

I wouldn't give him my mother's address, so my father went to the international electoral office to find it. Before he wrote to her, he asked me what I thought. "That's up to you," I said. He read me the letter he was going to send her, and asked me if there was anything I wanted to add. "No," I said. I really didn't want him to contact her, because for 15 months I had him to myself, just him and me.

But he sent the letter, and my mother wrote back, asking why was he getting in contact with her after 40 years? He read that letter out to me; it was very angry. Then he wrote to her again, telling her that he had been in contact

with me for a year. He gave her my phone number, and told her that she should get in touch with me. He was very persistent – I think that's where I get it from! He said it would be good for her to go and see Lorraine and me, that she had to do it. He couldn't – he was too far away. He really pestered her.

My dad kept calling my mum to tell her that she had go see her girls.

She contacted me to say she would come to see me when she came to see Lorraine. She was holding this up. I understand that she was frightened and guilty, but she never spoke to me about this.

Meeting my Mum

My dad's pestering definitely had an effect. My mum phoned me first, and then she wrote to me. Then, in 2002, my mother agreed to meet

me. She was going to come up to Sydney from Cooma, where she lived, and meet me at the Mercure Hotel at Central where Faye was staying.

Faye was my support person through all this. My mother spoke on the phone to Faye more than she did to me. My mother would not give me her phone number. She also didn't really understand what Faye's role was; Faye was my support person, but she was also Lorraine's advocate. A lot was happening with Lorraine at that time, and I wanted Faye to explain that to my mother.

Before the meeting, Faye and I talked about what would happen and what I wanted to get out of it. I really wanted to ask my mother why she didn't come back to get me, and to tell her how I was all alone in that institution.

Then all of a sudden, my family had come into my life, and I felt very angry and confused.

And in my heart I blamed my mother more than I blamed my father for what happened. But Faye and I decided not to go there, or my mother would probably walk out. This would be a one-chance, one-off meeting, and I didn't want to risk it. In the days before, I was so nervous that I was shaking. I was feeling all the things you would expect to feel before a meeting like this. I didn't sleep the night before, and Faye was very worried about me. I had never thought I would go through with this, and I had such mixed feelings about this meeting.

My mother had sent me a photo of herself, and I sent one of me to her. She told me I looked like my dad. My dad had sent me some photos of himself, so now I finally had photos of both my parents.

Before that, I had never seen either of them and I did not know what they looked like.

When my mother met me it was 1.00pm on 27 June, 2002. It was a sunny winter's day. The hotel desk rang Faye's room to say that there was someone to see me. Faye asked me if I wanted to go down; I said I didn't, so my mother came up to the room.

We waited for her knock on the door. I opened it, and I saw my mum for the first time.

I was overwhelmed, but I kept it together. I thought, I've got her eyes, but Lorraine and I are more like our dad. Since I've got to know Karen, I can see how much she takes after our mum.

I let her into the room. She tried to hug me but I held her off. Then she sat down. We offered her a cup of tea and a biscuit, which she took.

It seemed like she didn't really trust Faye. I started to talk about myself – my work, my friends, my sister, my relationship with Faye, and about living by myself. This is what Faye and I had decided would be best: I didn't want to talk about the very hard things. Instead, I went gently with her – after all, she was an older woman in her seventies.

But I didn't feel gentle. What I really wanted to do was punch her. I wanted her to hurt as much as I had been hurt. I wanted her to know what she had done to me, how things had been for me. But even though I was the child, I was also the parent then; I couldn't help it, I was making sure she was okay, and so I wasn't too hard on her. I also needed to see how she was acting towards me. Remember that she didn't even know that I could speak before I spoke to her on the phone! The doctors had told her nothing would come of

me. I could almost feel the guilt that was coming out of her.

This meeting went for about an hour and a half. I was so anxious that Faye had to remind me to bring up things that were important to me. I didn't ask my mother any questions; my process was to talk about my own life and how things were for me. I felt that it was better to do it softly and calmly, not to upset this woman who I didn't know from a bar of soap.

Afterwards, my dad rang me and he rang my mum as well to see how the meeting had gone. I told him that it had been very hard for me. He asked me how I felt now, and I said I was ok, but he didn't push. I told him that I had mainly spoken to my mother about all the work I do in advocacy.

My mum phoned me after the meeting, but I couldn't bring myself to talk to her straight away. A couple of days later she called again,

and I was more ready to speak. She asked me if I wanted to come down to Cooma and stay with her for a weekend. I said, "Yes." So a couple of months later, I took a train down to Canberra, then another train to Cooma to visit her. It was a freezing day. She met me at the train station. We had coffee in town, then we got a taxi to her place, which was up a steep hill. She gave me her bed to sleep in, and she slept in the spare room on a sofa.

We got on ok at first. This was all so new for both of us. But the next day she started going on about my father, complaining about him, telling me that they weren't married when I was born, and that he slept around. I didn't want to know this. Then she said, "Your dad says that you are everything to him. You mean the world to him." She was telling me that I was the apple of my father's eye.

I wanted to say, "If I was the apple of his eye, why didn't he feel like that when I was little?"

Why didn't you both come back and get me?
And why don't you feel like that yourself?" But I
kept quiet.

I felt so angry. I had a cup of hot coffee in my
hand, and I wanted to throw it at her. But I
went into the bathroom to calm down. She
came in, and tried to cuddle me, but I pulled
away. Then I packed up my bags and I told her
that I was leaving. She didn't say anything, but
she asked if I wanted her to come with me. I
said no. So I left with my bags, and I waited at
the bus stop for a bus to take me to the train
station.

She tried to call me for a couple of days, but I
didn't answer the phone. I had tried so hard not
to let something like this happen, and not to
blame my mum, but deep down I had always
wanted my mum more than my dad, and it
turned out the other way. I felt that she was
blaming me for getting into contact with my dad
instead of her, but that's not what happened.

My dad was the one who got in contact with me. I don't know how she felt about meeting me. Maybe she didn't want to do it; maybe she felt pressured into it by my dad. I wanted to ask her, but this was way too complex.

After that, I was in contact with her every now and again.

I spoke on the phone to my dad every single week for many years.

A time for celebration

*Kim's 50th birthday picnic
Centennial Park 16th November 2006*



9 The past catches up with me

In 2005, I was on the Disability Council, and we were doing a project on deinstitutionalisation.

They asked me if I would go back to see how – or if – the institution, Stockton, had changed. That was the place I grew up in. I agreed to do this, but it was very hard for me. I said we should look at how we could work with people at Stockton, to try to make sure that the residents had some quality of life, and to see how we could make things better.

Three people came with me: the Executive Director of the Council, the Secretary and the Council's support person. We talked to the

manager at Stockton. She had been there for many years and she remembered me. She took us around the hostels and group homes on the grounds to show us how different it all was from the past. It was now all about cluster housing, and the residents mostly had high medical needs. They all had their own rooms now. But it was all high security, and I saw that the staff had lots of keys on them.

We went to see the unit where I lived from age 14 to 20 years.

Before we went inside, the manager had to unlock the doors, and when we went through each section inside the building, more doors were unlocked and locked again. A young woman with high support needs came out of her room, saying “mummy, mummy”, all the time. She was nearly naked. The nurse tried to take her away, but I felt very strongly that she wanted to talk to us. We spent some time with her, but she was really upset. Then they took

her away to get her dressed, and we went in through another locked door. There were five sections in that building, and they all had locked doors that stopped people from coming or going.

Back when I was there, it wasn't a closed unit, and now it was. They told us it was for people with very complex needs.

Then we went into the main hall area.

I saw myself in a couple of pictures that were hanging on the wall. The manager asked me if I wanted a copy of them.

"No thanks," I said.

My feeling was that Stockton was still really bad. And we never got to work with the residents after all.

I started seeing a counsellor around this time, to help me deal with my past. I went to her for

about two years, on and off, and during this time I felt like I was going backwards and forwards. I made plans with the counsellor to go back to Stockton again, so that I could get the files that they had kept on me, but in the end, I couldn't do it. I couldn't go back there. Instead, my counsellor wrote a lot of letters about getting my file from them.

Finally, they gave the files to her, and I have them now. After two years, I knew I had to stop seeing the counsellor. I was getting too attached to her: she was around my mother's age, and we had to break the strings.



I ended up leaving the disability sector in 2006. The reasons I did this were all about people with an intellectual disability living in institutions. The government was keeping people in institutions, and I didn't think the

disability sector was working hard enough to stop this.

At that time a lot of parents were saying, “Ok I’m getting older, so what’s going to happen to my son or daughter? We don’t want them out on the streets; we don’t want them abused; we want them somewhere safe”. I heard this over and over and over. I understood that they were worried about their kids, but people kept coming back to say that keeping the institutions open was the answer.

CID asked me to speak at a big meeting at Blacktown RSL. It was a meeting for older parents who had adult children with an intellectual disability who were living in an institution. They were talking about how the government wanted to close one of the big institutions at Rydalmere and move the residents out into the community. This was a very good thing, but these parents didn’t want



Speaking out in 2006, before Kim took time out from the disability sector



Kim was passionate about creating accessible easy-read documents for people with intellexctual disability

their sons and daughters to move. The parents were saying, “I love my child, and I’ll do anything for my child, but I don’t want them to leave where they are. They have been there for a long time and they won’t be able to cope in the community.”

I tried to tell them what it was really like for a person with an intellectual disability to live in an institution.

These parents said they didn’t understand what was happening. Years ago, doctors and the government told them that their child should go to an institution. So that’s what they did. Now the government and the community were saying that it wasn’t right for children to be locked up any more. “What does this mean?” parents said. “Why did you make me do the wrong thing back then?”

I couldn’t take it any more. I walked out of that meeting. The parents kept saying they wanted

their sons and daughters to stay in the institution, and I got frustrated and angry. I suppose I should have been angry with the government instead of “parent bashing”. But that was what I thought back then. I understand things better now, because I had a chance to get to know my mum. Not that my mum was treated any differently from anyone else, but I’ve seen what happened to her. I’ve seen it through the eyes of a parent. Fifty years ago things were very different. I found out that my mum wasn’t in control at all. I had always thought that parents were really bad people.

But I still felt that I couldn’t be involved with all this any more. I was getting so edgy and angry with people, taking it out on everyone. There was talk all the time about cluster housing for people with complex needs, talk about putting people in boxes, as if they weren’t human beings. I don’t blame parents any more, I blame society.

PWD was organising a conference about accommodation and getting people out of institutions. Matthew, one of the PWD managers, asked me if I would speak at the conference.

I said, “No, I can’t be involved any more with this hot potato.”

But I agreed to tell my story for their newsletter, *Link-Up*. I agreed to tell them about when I was younger: my life at school, and my work in the advocacy sector. I told them about living by myself, and how I had to learn the skills for looking after myself. I said that no-one should ever be locked up. No-one should be forgotten. No-one should not have someone around to love and cuddle them.

That was very hard for me to do.

I didn’t want people to say that I thought I knew it all. I was speaking from my own experience

of damage and loss. I spoke about having a sister with high and complex needs. I spoke about my relationship with Faye, and how she became my sister's advocate. I thought I could handle talking about these things. But I couldn't. It was all too personal. Even though I knew Matthew pretty well, I felt overwhelmed when I had to tell him these things for the article. But I did it because I wanted my sister and people like her with complex needs to have a voice. If I didn't do it then who would?

PWD asked me again to do some talks around deinstitutionalisation, but I couldn't. I was still very damaged, and felt a big loss that my parents hadn't been in my life.

I know now where my hit points are.

My attitudes have changed a lot in the last two years. What I went through with my mum, during her last few months, opened my eyes. I understand more now, and I learned the tools

to speak with parents. I try to tell older parents that there are other ways of doing things, there are other resources to help them. But mostly they don't know how to get these resources, or their eyes are closed to them. I know that these parents are worried about what will happen to their children, what their quality of life will be. I know that parents don't know where to turn. Parents feel that the children are their burden to carry by themselves, and that they as parents are always being blamed.

But nothing makes it ok for people to grow up in an institution, like I did.

I was still on the Board of CID then. At that time the Disability Department wanted to put people with intellectual disability who had been in prison into institutions after they were released, so they could learn skills for living in the community. The idea was that people with intellectual disability or mental health problems needed somewhere to go to learn skills so they

didn't end up back in jail. The government got together with Rydalmere hospital, so that people would go there when they left prison. CID tried to stop that from happening. But CID also said that maybe it was okay for them to go somewhere for a little while, because they needed to get some help with living skills.

This made me very upset with CID, and I told them that that was not the way to do it. I admit that I was acting out a bit. I got so angry that I threw a glass at someone. I walked out and I resigned from the CID Board. The next day, Helena from CID tried to talk to me, but I would not listen to her. She rang Jim, to ask him to explain it to me, and I got angry at him. They were all very concerned about me. When I left the meeting with Jim, I went home and cried.

The next thing I did was to leave IDRS. I had worked there for 20 years, and I loved my job. But I couldn't do it any longer. I thought carefully about what I should do and what I

should say. I got someone to help me write a letter to the IDRS Board. I gave the letter to Janene, my boss. I said, “I’m not leaving because of IDRS. I’m leaving because of people in institutions.”

Janene asked me if I wanted to think about it first. She spoke to the IDRS Board about it. The Board asked the staff to talk to me, to give me a second chance. They gave me a couple of weeks to make up my mind. They said that after that time, they couldn’t hold the job open for me any longer. I had so many people telling me to be careful, telling me to think again, because IDRS had been such an important part of my life. My skills and my identity were all bound up with my work there. People from the disability sector kept asking me, “What will you do, Kim?” People from IDRS were ringing me all the time, saying, “Are you really sure? If you sit at home and twiddle your thumbs,” they said, “how will this help anyone?”



In happier times... with the Board at the celebrations for the 50th anniversary of CID

I told people to leave me alone. I felt like I had been knocking my head on a brick wall, trying to help people to have a quality life. But no-one was listening or caring.

Janene gave my letter to the IDRS Board. She told me that they were very upset to receive it; they even cried, because they thought I was doing such a wonderful job, and they didn't want me to leave.

But I did leave. I cut my ties with the disability sector and so I was pretty much on my own. People were still contacting me, looking out for me, but I needed time to think about where I wanted to go, and how I was going to get there.

This was a very hard time for me. I was very lonely. I felt very depressed. I had big problems with looking after myself, and with trusting people. People came knocking on my door. People were phoning me. People

showed me that they cared about me, but I was pushing them away. I couldn't help it. So many things were going through my mind, and I needed time to sort it all out.

10 On my own

I was going to a disability employment service before all this happened. I was working one day a week at IDRS, but I had also wanted to get more work in the disability sector.

They helped me get into a course in disability studies at St George TAFE.

I did this course for two months, with a support teacher in a mainstream class. I loved it and the people there thought I was doing a very good job.

But then I got really upset about the disability sector. I rang the teacher and told her that I could not go on with the course, and I was not going back. I told the employment service that I wanted to try working at a job that was not in the disability sector. My case manager there

tried to stop me from leaving IDRS. But I really wanted to look for work outside the disability sector.

We looked on the internet and saw that a child care centre had an apprenticeship in childcare going. My case manager rang the centre, and then I went in for an interview.

I had to think carefully about it. I was worried that if I saw young children crying it would bring back my own sad memories.

But I agreed to give it a go, and I started there on a three month trial, beginning with just working mornings for the first month, then going up to six hours a day. I was okay for the first month, but I found it really hard to get to the centre so early. I just wasn't used to doing this.

In that first month I learnt how to change nappies, sterilise bottles, bottle-feed babies as well as feed them mushy food and solids,

clean toys, interact and play with babies and young children, read them books, and talk. I spoke with the centre boss about going to TAFE one day a week, to do a certificate course.

After the first month, the boss at the child care centre wanted a meeting with my case manager and me. The boss said I had been going quite well, but then she said that she was not happy because I hadn't been turning up on time. I said that it was very hard for me, starting work at 7am and working five days a week. It was really too much for me – I hadn't done that for so long, not since I worked in the workshop in Newcastle.



Then, after one more month, I had another meeting at the employment service. My case manager rang the boss of the child care centre while I was there. The boss told my case manager that I was still not turning up on time. I was worried because the boss had not said anything to me about that.

In the past, if people weren't happy with me or had something to say to me, they always spoke to me first.

But I found out that if the client of the disability employment service was not doing well, the boss at the job had the right to speak to the case manager, and did not have to speak to the client first. I wasn't used to that. People I worked with always spoke to me first. So I got upset in that meeting. I said, "Forget about it now", but my head was going around in circles. I thought: I can't cope with this. I'm not going to be able to work in open employment.

I rang next day to tell my case manager that I was not going back to my job at the child care centre.

She rang the boss to try to sort things out: maybe my hours could be less, or maybe something else could get worked out. But I just left. I went back to get my things and to hand in their keys. I was the first person with a disability to work at that child care centre. Now they could give that job to another person with a disability.

After that, I had to meet with my case manager to talk about what I had done. I told her that I felt very let down because the centre boss hadn't spoken to me first. "Why did she talk to you and not me?" I said. It made me so angry. My case manager said that they had employed another person in that job. She told me that they put a lot of time and resources into getting jobs for people like me. "So what are we going to do now?" she asked.

I'd had enough, so I decided to take some time off. I didn't go to an employment service for about two and a half years. I just wasn't ready to go back to work. I couldn't do a job where I felt I didn't get respect. At IDRS, my job had been set up for me, and it fitted around me. I had a lot more time with the person I was working with. At the child care centre, the child was the important one, not me. That was very hard for me. I know I was spoilt at IDRS. I was the highlight there, but at the childcare centre, the child was the highlight.



For the next two and a half years, I didn't look for work, and I had nothing to do with the disability sector.

I didn't want to see the people I knew at all,
and when I did, I was sometimes rude to them.
I was very sad.

The reason for this was my feeling about
people with an intellectual disability living in
institutions. It was also because I really thought
that parents who had children with an
intellectual disability did not want them. This
was very painful for me.

My friend Jim knew that I was going downhill,
and that I wasn't looking after myself properly.
He said I should see someone. I didn't even
have a GP then. We met, and he helped me fill
in the forms to get in to the Development
Disability Clinic at Ryde. I was angry with him
then, for making me do that, but he was very
persistent. I said to him, "Okay, let's fill out the
forms." I really thought that the clinic people
would think my support needs were too low to
get into that service. I did get in, but it took a
long time for the appointment to come around.

Finally I went to see a doctor there, and Jim took me. Jim asked me if I wanted him to come in with me. He thought I wouldn't tell the doctor all the things I should, so I let him stay. That appointment went for three hours.

The doctor went through my whole history. It was very hard for me, going back over all that time. The doctor asked me questions about my family. She wanted to know how long I had been feeling upset. She asked me a lot of questions. She took my weight, and checked my sight, hearing, and blood pressure. She checked my breasts, and told me to have a mammogram at Prince Alfred Hospital. She wrote out a referral for blood tests, and told me I had to go to a place in Glebe to get that done. Then she made an appointment for me to come back to see her in three months' time. I found out after a few weeks that the results for the blood tests had come back normal. But I didn't go back for the next appointment. Jim

was very cross with me about that, but I told him, "This is my life, and I can do what I want". He kept trying to ring me, but I just wanted to be left alone. I did the same thing to Faye, and I wouldn't answer the phone. Faye got very worried about me, and she rang PWD to get someone to come around to my place and check on me.

I knew that Jim and Faye were trying to help me, by getting services for me, but I didn't want those services. I didn't want to keep being put in a box as a person with an intellectual disability. I thought that when they were trying to do things for me, they were just doing it because I had a disability. I thought they were looking at the disability, and not at me, the person. I just didn't want to be classed as a person with intellectual disability. All the things that had happened to me in my life so far were because I had been put in that box.


I was pushing away the people who really did
love me very much.



**What made me turn around and get
involved with the disability sector again?**

**That was all about seeing my mother again,
and changing the way that I thought about
her.**

11 Losing my parents ... again

fter he phoned me the first time, my father called me at least once a week, sometimes twice or three times, and we spoke for half an hour, or maybe an hour.

Over the next six years and five months I got to feel close to him. I even forgave my mother and my father for what happened.

I don't blame them, but I suppose I blame one more than the other. But I got to understand it all more through my dad, and I got to trust him more. We had a wonderful relationship, but it was my mother I really wanted to be closer to. So for that, I am blaming her more.

I hoped one day that I would be able to meet him, in person. But by phone was the way I met him, and over the six years we had contact, there wasn't one week when he didn't call. If he wanted to have the contact with his own flesh and blood and keep making the effort, then I couldn't say no.

During this time, I sent him a card every year, an anniversary card to mark when he had first got in contact with me.

At the beginning of March 2005, he called me every day for twelve days straight. Then I didn't hear from him for three weeks, but I didn't worry because I he had been calling me so much. Then I did start to worry, so I called his place and there was no answer.

I went to Redfern Police Station to ask about a missing person living overseas. They helped me contact the Australian Consulate in Germany. One day, when I got home, there

was a message from the police at Redfern waiting for me. I went down to the station, and they told me I had to ring Canberra. I called from the Police Station, and they told me that my dad had died two weeks ago. This was a very great shock, and I was very upset.

Afterwards, I phoned the hospital in Germany where he had died, to find out how it had happened. I asked if anyone had been with him, and they said no, he had been alone. I found this very hard for a long time and still do.

My greatest wish has been to go to Germany, to visit his grave in Frankfurt. But I never had the chance to do that.





Kim with friends at a remembrance event for her father after his death



Kim celebrates her father's birthday with friends, in the time after he passed away



One day in 2009 my half-sister Karen rang me and said that my mum was very sick in Cooma Hospital.

I tried to call my mum at the hospital, but they said she had already gone home. They wouldn't tell me anything. Then I found out from Karen that Mum was now in Canberra hospital. I rang Canberra Hospital; I gave Mum's name, and they told me she was in there.

I told them who I was – her daughter – and they were surprised. Mum had put down Karen as her contact person, and she had not told them she had other children.

I called Karen, and she was down in Canberra at the hospital. She told me then that Mum had cancer. I said that I needed to see her. I hadn't seen Mum for four years. I spoke to her on the phone, but only about once every six months. She never made the effort to see me.

The next day I went down to Canberra with a friend. The real reason I went down there was that I was still very angry with my mother. I wanted to tell her what I thought about her: that she was a mean and nasty person.

Before I went into the hospital, I felt nervous and scared, and I was actually crying.

Finally, I got brave enough to take the lift up to my mum's ward. A nurse showed me where to go to find her. When I saw her, my mum put her arms out to hug me, but I froze.

I wanted to tell her then that this was the last time she would ever see me.

I wanted to tell her then that she had been an awful mother to me, and I wished she had never had me.

But when I saw how thin and sick she was, I knew I couldn't go through with it. I knew she needed me.

At first I thought I would be down there in Canberra for just one day, but I ended up staying for three nights. I slept in the hostel that the hospital had for family members of patients.

On Friday, the second day I was there, it was just Mum and I, and she was sitting up in bed and telling me jokes, and talking about her life when she was younger. She had very hard life, really – she had come to Australia from Scotland when she was very young.

What I didn't know was that she was actually very kind-hearted. When I realised that, I texted some people to say that I had such a good a day with my mum – it was like all my Christmases had come at once.

Like she had never given me up.

I started to feel comfortable with her. I don't know if it was love that I was feeling. I didn't

talk about me at all then. It was just not the right time. The next day the same thing happened. Karen had gone back up to Sydney because she had to go to work, and she had her kids to look after. That gave me a chance, for once, to be alone with my mother.



There were five weeks from the time I found out my mother was really sick until she died. In that time there were quite a few days when I was with her on my own. I came down every weekend to see her at Canberra hospital for a month or so.

When she got sicker, someone in the bed next to her said to me, "Your mum is very lucky to have you".

When she got worse, she called for me, and I went to help her. I rubbed her back, and held

her hand, and cuddled her, and I stayed with her into the night.

Once she called for me at 4.00am, and the nurses phoned me at the hostel. I went straight to her then.

Before all this happened, I didn't know that at hospitals there were social workers for the patients. Karen told me that I had to get in contact with the social workers. But because she was put down as the next of kin, they didn't know anything about me, and they thought I might be a stranger.

I found that very hard to deal with. I also found it very hard that my mum had four social workers because she had been in different units at the hospital, and each unit had its own social worker. I had to see each one of them, and explain who I was four times. They all had a different story to tell about my mother.

These social workers tried to explain to me what was happening about her surgery and her treatment. It was very hard for me to understand, so I phoned Faye, and Faye called the social workers and the doctors.

There were so many different messages coming from different places that I got flustered. I found out then that I could get help with the cost of my room and meals because I was staying at the hospital as my mother's carer, and I was doing all this by myself.

So in the end, that's how I got to know my mum – through the process of seeing what was happening for her, understanding her pain, and watching it all rather than talking about it.

At first they wouldn't tell me anything because of confidentiality. Then I told a nurse I was her daughter, and the nurse talked to my mother

about it, and my mother ended up telling the nurse about her other children.

I finally found out what had been going on for my mum. First of all, the cancer was in her bowel, and she had an operation to take that out. That operation happened before I got down there to see her.

I found out from the doctor that she had died during that operation, but the doctors brought her back. But then they found more cancer, and she was going downhill. She was getting worse and worse, but they couldn't do any chemotherapy or other treatment because the cancer was too far gone.

When Karen and I were packing up the house after she died, we found a lot of letters from doctors going back to 2006 that were not opened. She could have known back then that she had cancer, but she didn't do anything about it.



Canberra Hospital (top) and Cooma Hospital, where Kim stayed with her ill mother before her death



Mum wanted to go home to Cooma. They had to make a plan because she lived up a flight of stairs, and she needed round the clock support.

The doctors wanted to put her in a nursing home close to Karen. To talk about this there was a meeting between Karen, one of the social workers and the doctor.

I was not invited. I went to find out where Karen was and what was happening in that meeting. The hospital staff told me where the meeting was, and I knocked on the door and went straight into the room.

“Excuse me, is this a meeting about Ellen Pein?” I said. “I’m one of her daughters. I want to know what’s happening.”

**I listened to them for a while, then I said,
“Over my dead body is my mum going to a nursing home.”**

Karen and the social worker said they needed to work out where was best place for her. But they listened to me, and they said then that she should go to Cooma Hospital.

My mother agreed to that. I went with her in the ambulance to Cooma Hospital, and helped her to fill in the forms, and get admitted. I stayed with her for a couple of hours.

She asked me to help her go to the toilet, in the ensuite toilet that was in her room. When she was in there, she called to me, saying she was very hot. She asked me to hold an electric fan up to her face to keep her cool.

I had to get the fan from the room, then hold it up to her face. It was very heavy, and she kept telling me to hold it up, higher, higher. I held it there for about ten minutes, until I thought my arms would drop off. Then I helped her get back into bed, and I rubbed her back because she asked me to. She was in a lot of pain.

I had to get away for a while, to have a break, and to book myself into the hospital hostel in Cooma. I went back later, and she was still in pain. She wanted me to stay with her, for about three hours. About 8.30 or 9 o'clock I went out to have something to eat.

At 12 midnight she went into a coma, and I left her then to go back to the hostel and get some sleep.

At 2am they rang me, and they said they didn't think my mum was going to last the night.

I left my room straight away, but I couldn't remember which part of the hospital she was in; it was all so dark and I couldn't recognise any of the buildings. I panicked, and started crying because I was lost and I wanted to get to my mother. I found myself in the maternity ward, and I told them where I was supposed to be going. They rang for someone to come

down and get me, and take me to my mum's room.

I had never seen anyone in a coma before. She looked like she was asleep, very peaceful.

I sat close beside her, and I said to her, “I forgive you for what happened to me.”

I said that a couple of times. I told her that Karen loved her, her grandchildren loved her, and I loved her. She looked like she was asleep.

About 8 or 9 in the morning I went back to hostel for breakfast and a shower. Then I went back to her room, and I sat with her for a while. She was still in a coma. The nurse asked me if I needed help to ring the buzzer if I needed to. I didn't. I could ring the buzzer quite easily by myself. An hour or two later I did ring that buzzer, because my mum's eyes opened. I

said, “She’s awake.” The nurses checked her, and then they told me.

She died at 3 pm on 13 March, 2009.

I screamed. I started hyperventilating, and I had to get my breathing in order. They asked if I knew anyone I could stay with. I needed someone, but I didn’t know anyone.

Then they looked in my mum’s file, and found someone, a friend of my mum’s named June. She came and took me back to her place; she was surprised because she had not known about me. I stayed with her until the middle of the afternoon, then she took me back to the hospital to see my mum.

The hospital rang Karen, and she came down the next day. June didn’t think I should stay by myself, so she organised a place, a sort of respite place, for me to stay for the weekend.

Faye came down from the North Coast straight after my mum died.

My mum was buried on 21 March, 2009. It was a long wait for the funeral while things got sorted out. Her family in Scotland was told, and they wanted her to have a Catholic service, and they wanted her to have a burial.

There was a lot of going backwards and forwards.



My dad's death was very hard, and when I found out my heart broke into two.


But I wasn't there with him when it happened. With my mum, it was a lot more complex. I found it even harder because I blamed my mum more than my dad. I wanted to know her more, but it was a lot more complex to do that, mainly because there was another person

involved in my mother's life: my half-sister Karen.

I can understand now a little bit about why mum and dad gave Lorraine, Robert and me up. But I will never understand why they didn't come back.

But I do understand a bit more about what things must have been like for them.

12 Where I am at now, mid-2011

 have my house – a Department of Housing flat in Redfern. I have a cat. And I have lots of crazy friends – some of them are real nuts!

I'm still trying to work out what to do and where I need to be. Those are not easy things for me.

I'm learning to understand more about what life is like for different people.

Like my sister, Lorraine. How she communicates with her eyes and her body language, and how she does things. I'm learning that she uses body language to tell me or show me how people like her, with high support needs and intellectual disability, communicate. That's where I am at with this at the moment.

Also, how it is for parents. Since I got to know my own parents, I've changed the way I think about them. I do not blame parents now for putting their child in an institution. What they did was wrong, but I'm trying to understand what it must have been like for them. My parents didn't have the same resources as parents have now, and they didn't have the same understanding that people have now, of what it was like for children growing up in an institution.

You can learn so much by being in someone's world. This is what everyone in the community should try to do.

I'm trying to work out how much work I want to do back in the disability sector now. I've done some things over the past year.

I spoke at a Conference in Dunedin in New Zealand, with Yvette from CID. In March 2011 I spoke at the In Control Conference in Sydney,

about people with intellectual disability having the right to make choices about their own lives.

I'm trying to work out what's my best fit. If I go back to the disability sector, maybe it will have to be in little steps first, doing things that don't upset me and push my buttons. I can't let that happen again.

I live by myself and I'm a very independent person. I don't like asking people for help unless it's the very last thing. I do my own shopping and banking – I'm just like everyone else. And if someone treats me as if I'm not like everyone else, I will tell them what I think!

So after all these years, I am still trying to work it all out: how to fit in work-wise and relationship-wise, and how to join with everyone as part of the community.

Kim Walker

June 2011



*At the "Having a Say"
conference in Geelong,
in February 2011*



*In November that year, in
Mullumbimby with Faye
(right), and friends Diana
and Joe*

Afterword

In 2011, Kim felt a lot better about her life than she had for a long time. She had always kept her home very private but then she started having friends around. Kim started to get involved in advocacy again. She did lots of work on NSW CID's health fact sheets.

But in July, Kim got sick. She had cancer. It progressed quickly and she died on Christmas night.

Faye Druett spent those last months making sure that Kim knew how much she was loved. Kim stayed at Faye's place at Mullumbimby and then, when her medical and support needs increased, in the local hospital. Faye was backed up by a fantastic team of Kim's friends who live near Mullumbimby.

Kim did not like going to the hospital. "Even though they are really good here, it's still an institution," she said. Kim's friends helped make her hospital room as personal as it could be. The walls ended up covered with photos and messages from friends.

Lots of Kim's friends came from Sydney to see her. So did her sisters Lorraine and Karen. Kim said that she was shocked to find how many people loved her.

For many years, Faye had been the most important person in Kim's life. Their relationship was hard to pin down – in some ways friends, in some ways like sisters and in some ways mother and daughter. Before she got sick, Kim used to say that she could not imagine living without Faye. She was scared that Faye would die before her.

Kim's relationship with Faye became even stronger in the last months of her life. They talked and talked about Kim's life, her illness, how she wanted to die and what would happen after she died. Kim appointed Faye as her enduring guardian so that Faye could make decisions about her treatment if Kim became unable to. This was a big step for someone whose life had been controlled when she was in institutions and who valued her freedom immensely.

Kim made Faye promise that she would be holding her hand when she died. And so, Faye sat by Kim's bed for the last four days holding her hand. On the night Kim died, Faye had to leave the bedside briefly to go the bathroom. Kim seemed to be in a deep coma. Faye told Kim she had to go for a bit and Kim let out a cry of anguish. Kim did this each of the few times that Faye had to let go of her hand. Kim

wanted to be connected to Faye, until she left Faye.

After growing up in the institutions, for decades Kim had fiercely guarded her privacy. She also said that she found it very hard to really trust people. She had lots of good friends but she was careful how much she disclosed to anybody.

In those last months, Kim became more open and trusting with her friends. It was as if she finally accepted how much they cared about her and that, with her life coming to an end, she could open up to people. She let people see her at her most vulnerable, something she had avoided until then. Perhaps she realised just how much she had contributed to the world.

As always, Kim showed that stereotypes about what people with intellectual disability can

understand are rubbish. When her specialist, Jo, gently explained that the cancer was spreading and that it would not go away, Kim responded, "That's not much time left on this earth is it!"

Through her adult life, Kim felt a sense of unique pain from growing up in the institutions and without her family. That's why she wrote this book. She wanted her story to educate and influence politicians, service providers and parents.

After Kim died, many friends and family came to Mullumbimby for her funeral. Later, Redfern Town Hall was packed with people who came to celebrate her life.

We followed Kim's request about what should happen to her ashes. Some of her close friends had them for a month each. Then, we had a picnic at Malabar Beach and released

her ashes into the ocean. We each released a pink balloon and watched as they soared into the sky. Kim was free.

Faye Druett and Jim Simpson



Redfern Town Hall is packed for Kim's Memorial on 6th February, 2012.

CID Chairperson, Fiona McKenzie, leads Board members in honouring Kim's legacy.



List of acronyms

CID	New South Wales Council for Intellectual Disability
DOCS	NSW Department of Community Services (now Family and Community Services)
DoH	NSW Department of Housing
DSARI	Disability Studies and Research Institute
IDRS	Intellectual Disability Rights Service
NCID	National Council for Intellectual Disability
PWD	People with Disability Australia Incorporated
SORO	Speak Out Reach Out

RSL	Returned Soldiers League (as in RSL club)
-----	---

UN	United Nations
----	----------------

TAFE	Technical and Further Education
------	---------------------------------

Kim Walker was a leading advocate for people with intellectual disability.

This came after she grew up in disability institutions and without contact with her family. These experiences left Kim with traumas that tormented her for the rest of her life.

But Kim used what had happened to her to try to stop it happening to other people.

This book tells Kim's story, beginning with her childhood in institutions, through the challenges of becoming independent in the community, to her work as an advocate. This included working as an educator at the Intellectual Disability Rights Service in Sydney through to representing Australia on the self advocacy committee of Inclusion International.

We also hear Kim's voice describe how she tried to find a family she had not seen since she was a small child.

In her matter of fact way, Kim tells us the story of her life to explain why no child should grow up in an institution and separated from family. Kim's story provides a powerful case for what she most wanted - all disability institutions to be closed and all people with disability to have a good life in the community.

Jim Simpson

Senior Advocate

NSW Council for Intellectual Disability