



President's Column

This edition of LinkUp focuses on an issue of fundamental importance to people with disability – deinstitutionalisation and the right to live in and belong to the community. Living in the community is a basic right that most people take for granted; one which includes the right to participate in the community just like everyone else.

For many people with disability the struggle to achieve this basic right is demanding, frustrating, and on-going. Unfortunately, it takes years of struggle to make the dream of community living become reality. The shameful fact is that the right to live in the community is still being denied people with disability in Australia. The bottom line is that this situation is not acceptable.

Since our establishment as the Handicapped Persons Alliance in 1980, we have advocated for the right of people to live in the community. PWD is firmly committed to continually

advocating for the realisation of the right to live in the community. Furthermore, we firmly believe that to be as successful in our advocacy as possible we need to participate in many different ways and at all levels - state, national and international.

At a state level PWD members, Board and staff participated in a forum of friends and family of people with disability currently living in an institution in NSW. We had the opportunity to share our experiences of institutional living, in comparison with our current lifestyles in the community, the benefits and, invariably, the challenges we encounter. The presentations were a testimony to the determination and commitment our members have towards the critical role of self-determination and representation by people with disability, for people with disability. It highlighted how people with disability can reach their full potential through living in the community.

The personal accounts that were provided at the forum form the basis of this edition of LinkUp. PWD sincerely thanks Jan, Tom and Kim for sharing their valuable experience, knowledge and insights.

PWD members also have had their say in a members' forum about NSW Government changes to desinstitutionalisation and supported accommodation policy. Members told us that:

- it is not acceptable that people with disability still live in institutions;
- community living can enable the development of long-term informal networks that enrich and sustain all our lives;
- community living can give us a sense of who we can be and who we are;
- the NSW Disability Services Act (DSA) is the appropriate policy framework by which support services to people with disability can and must be delivered;

continued on page 12

Contents

- 2 My life beyond the walls**
- 4 Injustice and living in institutions**
- 8 Amber's story**
- 10 A change of lifestyle**

My life beyond the walls

Tom Ferguson



From the time I was born, with cerebral palsy, until my adulthood, I lived in institutions. These were Griffith Hospital, where I was born and lived until I was 18 months old, North Ryde Psychiatric Centre till age three and a half, and McLeod House, a large institution (now closed) run by the Spastic Centre, for 20 years after that.

The next place I lived in was a boarding house in Stanmore, Sydney—it was appalling. After a couple of months at the boarding house, I moved to Northcott Society supported accommodation in Beverley Park for six months.

At this time in my life, I was a very angry man and would lash out. Because of this, I was moved to Gladesville Hospital (a psychiatric hospital). At the hospital, they kept giving me needles—you have no idea what I was going through—I was given no counselling, they just kept drugging me.

After Gladesville, I went to Bathurst of my own accord and stayed with my parents. Then, because of my anger, I spent

a week in Bloomfield Hospital in Orange (another psychiatric hospital) and a few weeks in Prince Henry Hospital. I then moved to Carinya Oaks, a privately owned boarding house, and lived there for about a year.

While I was living at the boarding house, the Spastic Centre told me that if I 'woke up to myself', in six months they would help me to find other accommodation. After six months, they came back and told me that I would have to wait for 3 years. I had really had enough; I was bored and depressed. I was determined not to stay at the boarding house any longer. Even though I felt a bit scared, I wanted to have a go at living independently in the community.

I contacted a friend of mine, who knew somebody in the Department of Housing. I gathered letters of support and applied to the department for my own unit. That was in November 1991, and by April the next year, I had a unit at Gorokan (near Wyong, on the New South Wales Central Coast). I lived there for seven years and then moved to East Gosford, where I have been living for eight years. I am now 42 years old.

Life at McLeod House

I lived for 20 years at McLeod House, an institution for children with cerebral palsy run by the Spastic Centre. I was not able to live with my family; it was not possible in those days. I used to go home to my family during Christmas and other school holidays though. Doctors told my parents to forget about me, but they never did.

One hundred children lived at McLeod House. There was no privacy at all. We lived in dormitories, eight boys to each dorm. I was 22 before I had my own room.

McLeod House was a lovely, large, old building, but they could have improved it by putting in single rooms for everyone.

We ate in a dining room, the adults at one end and children at the other. There was a boys' wing and a girls' wing; we were kept apart. If we were caught playing together we would be in trouble: we would be taken to the matron's office and would be grounded.

There was physical abuse of the residents by the staff, particularly in the boys' wing. People were hit and kicked.



North Ryde Psychiatric Hospital,
Photo: Government Printing Office
Collection, State Library of New
South Wales

They wondered why we were so angry—we were being abused. The staff hid the abuse, there was no-one to listen to us and no-one we could complain to. The matron was also strict. With today's laws, they would be in trouble for what they did to us.

This is why I am really passionate about how residential care services are run, why I am studying disability work and why am I am involved in PWD.

McLeod House has now closed and everyone who lived there now lives in group homes.

I did have some positive experiences at McLeod House though—it wasn't all bad. All the kids were like one big family and they really became my family. I also made some very good friends there and I am still in contact with one

of them. I have memories of playing cricket, rugby and other games with medicine balls, which were great fun. Many of the staff were good too, except the wardsmen, who would cause trouble.

“When I moved into my own unit ... I started my new life on my own in the community. I felt in control of my life for the very first time.”

My life today

The person I am today is not the person I used to be. There were many times I felt frustrated and angry. At the time I didn't know why, but looking back, I realise it was because I was locked up in an institution. There, we had no privacy, nor much say in what happened to us. I had no control over what happened in my life. All decisions about me were made by doctors, therapists and nurses.

What I'd lived through made me angry: not being in control of my life and I hated being dictated to. I started a program in reality therapy, which helped me to deal with the anger and frustration and to put myself

in the other residents' shoes. I began to tell myself: “Tom, wake up to yourself.”

When I moved into my own unit at Gorokan, and with the help of support services, I started my new life on my own in the community. I felt in control of my life for the very first time. I have since discovered many positive things about living in the community. In addition to being able to run my own life, I am a lot more relaxed and have made a lot of new friends. It is heaven living on my own; I don't have to answer to anyone.

Since moving into the community, I've attended TAFE college and completed my school education to year 12 and courses in computer applications. I am currently studying for a Certificate III in Disability Work and hope this will qualify me for employment in the disability sector.

To people who think institutions are a good idea, I would say “Wake up to yourselves.” Institutions ruin people's lives and hold people back from what they are able to achieve. People with disability should be given the opportunity to live independently as this allows them to explore their own identities.

Injustice and living in institutions

Kim Walker

I was born in Tasmania on King Island in 1956. My parents were living in Tasmania at that time as my father was working in the electronics industry there. I was their first child. They did not know I had disability, although my mum told me that when I was born, the umbilical cord twisted around my neck and I could not breathe.

When I was an infant, we moved to Adelaide. My parents noticed that I was delayed in speaking and so they took me to a few specialists to see if they could help. One told my parents to put me in a home and forget about me—that was the best thing for me. He said that nothing would come of me: I wouldn't learn to live by myself in the community or have friends. My parents weren't told that I had intellectual disability.

Just before my third birthday, I was put into an institution in Newcastle called Watt Street. People with psychiatric disability still live there today. I was there until age 14. My dad said they thought I was only going to be there for a holiday.

It turned out to be a really long holiday!

I remember my mum visiting me at Watt Street when I was eight. We went to a cafe for a milkshake and she brought me a colouring book and pencils. I don't remember her visiting before that. I have letters that say that she sent me money, presents and clothes, but the staff at Watt Street wrote to her and told her it was best that she stay away from me.

When my dad was away working on a ship, he sent me a cake. The staff wrote to my dad and told him not to do this because it would make the other children jealous. I think it was because they did not want me to get presents. My dad apparently came to see me every so often, but I can't remember this.

My parents were not given a choice about me moving into an institution. Unfortunately, society had decided that because something is not working with someone, nothing will come of them. This is wrong. I feel for my parents, as they were not offered the support that parents of children with disability get today. They were not given a pension and they were told that putting your child in an institution was the best thing

to do.

When I was in my forties my parents came back into my life and were able to start to help me to deal with having lived in an institution.

“I feel for my parents ... they were told that putting your child in an institution was the best thing to do.”

Living at Watt Street

I don't remember much about living at Watt Street, even though it was for 11 years of my life. Some things I do remember are: Watt Street was a big building. I was always kept in a locked room, which I shared with other children. Parents came to see their sons and daughters, but most of the time; no-one came to see me. I used to rock back and forth a lot because I was unhappy. I went to school in the Watt Street grounds. A wardsman told my parents that I was a very likeable child.

I am still trying to recover memories from this part of my life. I hope I remember more one day.

Moving from Watt Street to Stockton

When I was 14, they moved the children from Watt Street to other institutions. A group of us went by bus to Stockton, another institution near Newcastle. They did not prepare us for the move: they did not tell us when we were moving, who would be going with us, or what it would be like there.

We moved in January 1970. I moved with a group of about 15 who were going to go to school. None of them were my friends; I did not know what friends were then and I was a lonely child.

I was frightened about going to Stockton; I didn't know why I was going there or what it would be like. It was bigger than Watt Street and there were children of different ages, from 6 to 18 years old. There were only children in the unit I moved to.

Living at Stockton

It took me a while to settle into living at Stockton. I shared a room with five other girls. Some of the staff there were good and others not. The staff who were nice and tried to make life better for us got

into trouble for it. Other staff treated me like I didn't exist and I was not important.



Newcastle Mental Hospital at Stockton

Photo: Government Printing Office Collection, State Library of New South Wales

I went to school on the grounds of the institution. The teachers were good and kind-hearted.

Sometimes we would leave the grounds and go to sporting events, movies and occasionally, on holiday.

One of the staff let us get a dog, who we called Rusty. We found him on an excursion to the Hunter Valley. He was 12 when we got him—we had saved him from being put down. Rusty would stay under the teacher's desk in our classroom. We taught him tricks and took him on outings with us. He was with us until he was 19. The staff said he was hit by a truck, but I suspect

that they had him put down. Or maybe he was sick from being so old. One of the best things about being at Stockton was being able to take care of Rusty.

I made friends at Stockton and I am still friends today with a person I met while I was living there.

Bad things also happened at Stockton. When you got upset, the staff would tie you to a chair that had leather straps for your legs, arms and body. They laid the chair on its back so that you would not fall forward if you rocked it. You might be left like this for a couple of hours. This only happened to me once; they said it was so I learnt to behave.

They also used straitjackets on kids and gave kids needles to calm them down. Luckily, this never happened to me. There was also a time-out room—a small room with nothing in it. I used to go in there and try and calm people down. They would often drug the kids who were sent there. Some would have to stay in there all day.

I learnt very fast how to keep out of trouble.

If you played up at mealtime, the staff would take your food away and you had to watch the other children eat. They would also punish you by making you eat things you didn't like. If you accidentally made a mess on the table, you would not get a token that would entitle you to a reward.

Sometimes people would get violent because they were so unhappy. I was hit by other people and almost had my eyes gouged out once.

Moving out of Stockton

“It took a while to get used to living in the community ... for most of my life, I did not know what happiness, friendships or choices were.”

I was 20 when I moved out of Stockton. At the time, I

was living in a house on the grounds, where I was learning independent living skills. One day, I was told I was moving out. They did not prepare me for this; they told me nothing about the move. With three others, I was moved into a hostel in Newcastle with other people with disability. The hostel was run by family members of some of the people who lived there.

I was very unhappy and scared at first and I didn't understand that the hostel was my new home. I packed my bags and took a bus back to Stockton. There they told me that I didn't live there any more and called someone from the hostel to pick me up. I went back to the hostel under protest. I lived there for about five years.

Living in the community

It took a while to get used to living in the community and having freedom and choices. Because I was in institutions for most of my life, I did not know what happiness, friendships or choices were. I was very unsure of myself at first and did not know what the world would mean for me.

I now live by myself in a Department of Housing unit in Sydney. Sometimes I wish I

had a housemate, but at other times, I am glad to be on my own, not sharing my space. I like looking after my two cats, Whitey and Black, who give me cuddles and love.

I have been working in the disability rights sector for 17 years now. I love my work and I've learnt how to relate to people through working.

I have many friends now: people I can talk to, go to dinner with, and call on for support. I am in charge of my life now, I make my own decisions and I am free. No-one tells me what to do or when, what I have to eat, or when I have to go to bed—I can do what I like whenever I like.

Really bad things happen to people in institutions. When I was living in institutions, there were not any disability rights organisations. If there had been, the government would not have been able to do those things to us. I am so pleased that people with disability today have the support and resources that we did not have back then.

Living in the community can be hard, especially when you've been in an environment where you are told nothing will come of you. Of course, I have shown

them they were wrong all along.

About my sister, Lorraine

When I was 14 years old, I was at a sports carnival when a teacher said to me: “I think I know your sister, Lorraine. Is she your sister?” That was the first time I learnt about another member of my family.

Lorraine was living at Stockton at that time. After I was transferred there from Watt Street, I asked about her but by then she had been moved. I asked where to but they said that they didn't know.

Because Lorraine was moved around between 14 institutions she did not learn how to manage her behaviour, skills that I learnt or how to communicate using language. I think her development was delayed by being moved so much and not getting the right support. In her early childhood, she was apparently walking and talking as most children do. Now she is described as having a severe level of intellectual disability. Lorraine can have a conversation, but cannot use complicated sentences.

I first met Lorraine in 1985 or 86 after I went back to

Stockton to find out about my family. I asked for help trying to find her and found out that she was living in the state-run institution at Rydalmere. I went with a friend to visit her.

I had a big shock when I saw Lorraine; she has a greater level of intellectual disability than me, her appearance was quite different and the way she responded to me was not what I expected. I did not notice that we looked like sisters.

To begin with, I would visit Lorraine once a year and I would not spend a lot of time with her as I found it very upsetting. I didn't really want to know her or for her to be my sister. This all changed in 1997 after she had a bad accident and almost died. The hospital called me and said that she was in a coma. I visited her and saw how unwell she was—it was very scary. She was in a coma for 10 days and I visited her every day. Thankfully, she got better.

I went to the Guardianship Tribunal for a guardian for Lorraine. I was her joint guardian for a long time. I promised her that no-one would ever hurt her again. After this, I really got to know her and have kept this commitment to her ever since.

Lorraine continued living in Rydalmere until March 2002. Many people thought that she should stay in an institution but I refused to accept that anyone, particularly my sister, should live in an institution. We fought to get her out—wrote many letters and went to many meetings—and finally it worked.

Lorraine now lives in a group home with 3 other people with intellectual disability and high support needs. She is doing extremely well in some areas of her life but other things are still difficult for her. Overall, her quality of life has improved, she has grown in lots of ways and her life is richer. She has taught me that people with high support needs can live in and be part of the community.

I visit Lorraine every 2 weeks and spend time with her. We read books and magazines together, and sometimes go for a walk or to a café. We now know each other very well. Lorraine is not only my sister, she is my best friend.

Amber's story

Gayl Foy

Amber was born with cerebral palsy 29 years ago. At age 18, she had an operation for a spinal condition in which rods were inserted into her back. Since then she has never been the same.

After the operation, she couldn't walk anymore and became incontinent and epileptic. In 1995, when Amber was 24, I couldn't cope caring for her anymore, so I looked around for supported accommodation in Casino. There was none, and it was very likely that there wasn't going to be any.

Because of my deteriorating health, my only option was to put Amber into an aged-care facility. That was six years ago. Amber hated it there and I hated putting her there. It broke my heart to see her there.

Amber lived with about 80 frail elderly people, including people with dementia. No-one talked to her because they thought that because she could not talk, she could not understand them.

Some of the elderly residents complained when she started yelling out when there was

something wrong with her. She was often been put in her bedroom with her music on and the door shut so that she wouldn't upset the elderly residents. She was told to "shut up" and that she was "a naughty girl" by some of the residents.



*Amber Foy and her mother Gayl.
Photo: The Northern Star*

She was woken at 6am, showered, given breakfast and then put back to bed, fully dressed, until someone from her ATLAS group picked her up. She was put to bed at about 6pm when the older residents are in bed.

Amber received no therapy; she had the occasional five-minute walk on a walking frame along the verandah. The muscles in her legs deteriorated.

Instead of her food being mashed, it was pureed, like a baby's. She is able to feed herself some finger-food, but

because there were so few staff at the nursing home, they found it quicker and easier to feed Amber themselves. She was never given a choice about what she would like to eat or drink, nor was she ever asked if she would like something.

She would have liked to be able to choose what she would like to eat or drink and what time she went to bed. Amber could not have those options because a nursing home is basically an institution, run on timetables. There was no extra time for a young person with disability, who has very different needs to those of the elderly people for whom the nursing home was designed. A nursing home receives a set level of funding, which is never intended for the support of a young person in need of rehabilitation.

While her basic physical needs were being looked after, Amber's emotional and social needs were not. She was depressed and withdrawn, and who wouldn't be, with people older than your own grandmother as your housemates. An aged-care facility is no place for a young person like Amber, or any other young person. Amber loves to socialise with her friends and family, and with people her own age, who have the same interests.

Amber was re-assessed by the NSW Aged Care Assessment Team in September 2003 at my request. They recommended that Amber be given access to a high-support home.

I started writing to the NSW Minister for Disability Services in September 2002. I also continually wrote to other state and federal politicians.

Governments are meant to safeguard human rights and

encourage full citizenship. Amber is a citizen of this country but was denied such basic human rights as inclusion in the community and the chance to contribute to society.

Amber did not want to live the next 60 years of her life in a nursing home.

In November 2004 news was received that a vacancy had been found in a DADHC group home. In December Amber

moved in. From day one her emotional and physical state improved.

Amber is now enjoying her life. There are challenges that need overcoming, but she is now happier and has a say in her life. I have kept a written and photo diary of Amber since her move. These show that living in the community is not some esoteric argument. For Amber it has made a real difference!

PWD Individual & Group Advocacy Service

Do you need help to solve a problem?

We may be able to help. We help people with disability sort out problems such as:

- someone is abusing you
- someone discriminates against you
- you are not getting a good service
- you cannot get a service you need
- you have a big change in your life

We help by providing:

Information: about your rights and where you can get help

Mentoring: talking to you about ways you can solve a problem yourself

Advocacy: working with you to help solve your problem



We provide a non-legal advocacy service for individuals and groups of people with disability who live anywhere in NSW. We

also provide information to people with disability, their family members, carers, disability support workers and others. Anyone can call us for information and advice.

Our service is free!

Please contact us on:

Phone: 02 9370 3100
Toll Free: 1800 422 015
Fax: 02 9318 1372
TTY: 02 9318 2138
TTY Toll Free: 1800 422 016

A change of lifestyle

Jan Daisley BEd (Habilitation)



I acquired multiple disability in my late teenage years, after which I spent three years in rehabilitation. Not a lot could be achieved through rehabilitation, unfortunately. I then went to an institution for people with disability in Ryde, Sydney called Weemala.

For the next 30 years, I was abused and disempowered by the staff and hierarchy at Weemala, as were most of my fellow residents. We stuck together and tried everything in our power to gain some independence and control over our lives, but all the authorities would say was “We know what is best for you.”

In 1992, I heard there was a possibility of eight residents moving from the institution into group homes in the community. I was one of the first to put my hand up. My parents were against the idea, but I was determined to give it a go. For the next 18 months, I investigated my options and planned everything to ensure a smooth transition.

On 9 August 1993, I left Weemala to start a new life.

The hardest part was leaving all my friends, particularly my best friend Jill, with whom I had shared a room for 30 years. She said that if I was successful, she would consider moving out herself further down the track.

I can't say that it was easy at first. There were many difficulties, which we overcome with commonsense and determination. One of the registered nurses at Weemala told me I would not last a week in the outside world—I told her to go to hell.

Once I was settled in my new home I started writing my autobiography, which was I something I had dreamt about doing for a long time.

In 1998, I applied for a job with the then NSW Department of Ageing and Disability. I won the position and spent the next three years in an advisory role with the department. About the same time, I was asked to join the advisory committee for the Disability Complaints Service at PWD. I took up the offer and enjoyed working on the committee very much.

I decided in 1999 that it was time for me to further my education, so I enrolled at TAFE and obtained certificates

II, III and IV in Disability Work. Then in 2000, I began a university degree: a Bachelor of Education majoring in Habilitation. At the same time I took very ill, but I was determined to carry on. I completed the degree in October 2003 and graduated in April 2004 at Sydney Town Hall.

After graduating, I took a year off from study to finish my second book, which I am still in the process of writing. My second book is a sequel to both my autobiography, and John Roarty's *Captives of care*, which is about life in Weemala.

In 2002, I was elected to the Board of Directors of PWD, and this year, was elected Secretary. I have also started a masters degree this year.

I could not have achieved any of this if I had remained living in the institution. And I owe my success to my family and friends who have supported me the whole way through. I am a great believer in devolution, and I will advocate for and do everything in my power to assist those who are still institutionalised to make a successful transition into the type of accommodation and lifestyle of their choice.

“We stuck together and tried everything in our power to gain some independence and control over our lives, but all the authorities would say was ‘We know what is best for you.’”

I believe every person, regardless of how profound their intellectual or physical disability, has something to offer that can benefit our community. I know many such people currently living in group homes.

With the appropriate support, people with disability can have a better quality of life in the community than they would in institutional living. As a community we should join together to make this a reality.

My first book will be published in October this year, I am proud to say, thanks to the sheer determination of many of my devoted friends to whom I am most grateful.

Jan Daisley’s ‘I hear more than you see’

I hear more than you see is a fascinating and moving autobiography, detailing Jan Daisley’s journey through a horrific accident, rehabilitation, institutionalisation and finally to a home in the community.

Jan is portrayed with an immense resolve to regain her life after the accident, shown through the many battles and campaigns that she fights, along with the people she lived with in the institution, for fairer living conditions and basic human rights.

Throughout the book, the importance of family, friends and faith run as central themes. Several important relationships keep Jan grounded and supported in her struggles, and the unfolding of some extraordinary friendships show both the esteem in which she is held by others and the importance of those friendships in defining and redefining oneself.

To order *I hear more than you see*, for \$27.50 (including postage) please call Zoe Brownfield on 02 9817 3639.



President's Column

continued from page 1

- current service options are not appropriate or relevant especially to Aboriginal people with disability and people from culturally and linguistically diverse (CALD) communities.

Our members also recognised that for all the benefits of living in the community, it is also very difficult for some people. Most of these difficulties arise from an under-resourced service system that supports people with disability living in the community. The service system is stretched beyond its limits and therefore can not adequately meet the needs of people with disability. PWD will continue to advocate for a fully funded service system that allows people with disability to live in the community.

At a national level, PWD continues to advocate for a concerted, fully funded intergovernmental initiative to relocate, within the next five years, all young people with disability from residential aged care to supported accommodation in the community. In particular, PWD believes that these services must operate under state and territory disability services Acts, and that diversionary measures and funding arrangements to prevent

any future admissions must urgently be implemented. We have also called for changes to the Commonwealth State and Territory Disability Agreement to enable the funding of blended community service and clinical support services where this is necessary to support the person to live in the community. While there has been some recent (hopeful) announcements through the Coalition of Australian Governments (COAG), PWD remains concerned that the 'buck passing' between State and Federal Governments continues to allow this deplorable situation continue.

Amber Foy's story in this edition of LinkUp provides a very personalised and stirring account that relocation from a nursing home is possible for young people with disability. Amber's life has improved immeasurably as a result of her successful move into the community. The article is also testimony to the tenacity of Amber and her family, particularly her mother, Gayle, in not giving up on the dream for a better life for Amber.

PWD has also been involved in advocating for accommodation options in the international arena. Discussions during the ongoing development of the United Nations convention on the human rights of people with disability include debate on community living. PWD has played a very prominent role in this debate. Not only do we advocate deinstitutionalisation,

but also that governments be obliged to develop devolution plans to facilitate this outcome.

This edition of LinkUp gives us personal insights into the importance of making sure all people have the right to live in the community. I hope that the messages that all the contributors to this edition send are conveyed to decision makers at all levels: we want and have the right to live in the community.

Contact us

LinkUp is the newsletter of People with Disability Australia Incorporated. We welcome contributions from members.

If you would like to receive LinkUp in an alternative format, or have an enquiry, contact Allyson Campbell.

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