

A PEOPLE FIRST NEW ZEALAND PRODUCTION  
A PLACE OF OUR OWN

In April 2009, People First New Zealand initiated a unique road trip. We wanted to find and listen to those who had stories to tell of their lives in institutions such as Kimberley and Templeton, and their lives now, living in the community.

Graeme Parish, People First's current National Chairperson, himself the former resident of an institution, was chosen as guide and interviewer. Travelling across New Zealand, Graeme met and interviewed a varied group of people with deeply compelling stories. For some, community care has allowed an escape from the abuse suffered in institutions. For others, life in the community is a constant battle against prejudice and discrimination.

This book, developed from the documentary of the same name, tells the stories of four unique individuals, as told to Graeme Parish. Their stories remind us of the journey thousands of people have had from institutions to community living, and of past and current issues. Alongside their stories, pressing issues are explored in-depth by well known researchers, change agents and authors working in the field of disability.

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Living with the legacy of institutionalisation





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This book is dedicated to all those who have lived in institutions in New Zealand,  
whose stories will never be told.

*He kupu maharatanga mo te hunga tūroro kua okioki,  
me tā rātou reo kua ngaro i te pō.*



# Contents

Preface	7
Foreword	8
Meet Graeme Parish	11
The road trip begins	13
Meet Sharyn Haig	14
Sharyn, Stewart and April at home	16
Creating a place of our own as a family	19
Meet Murray Priest	25
Murray at home	27
Institutionalisation in the community	31
Meet Rolly Baker	37
Rolly at home	39
Listen to me: Effective communication in a place of our own	43
Meet Kevin Thompson	53
Kevin at home	54
Kevin and Rolly reunite	56
'No man is an island': Finding a place in friendships and relationships	57
People First New Zealand Inc.	64





# Preface

Historically, many thousands of people with a learning disability lived for all or some part of their lives in large institutions around New Zealand. It is generally acknowledged that at the height of institutionalisation around 12,000 people resided in institutions across New Zealand.

The last large institution, the Kimberley Centre in Levin, was closed on 20 October 2006. However, as many People First members report, institutionalisation is not only about the buildings and the location, it is about how things are done, how support is provided, who gets to choose and who has the power.

In 2008, the Frozen Funds Charitable Trust had funding available under the theme 'Raising the public awareness of the legacy of institutions.' People First New Zealand applied with the idea of recording the stories of people with learning disabilities, to find out what their time was like living in the institutions, and what life has been like since. From this idea, People First decided to make a documentary and book, and to hold two forums to discuss the issues raised.

I trust that by reading this book you will remember the journey of institutionalisation that many people with learning disabilities experienced, and that you will think deeply about the policies and practices that continue today, left over from that era.

Cindy Johns  
National Manager  
People First New Zealand  
Nga Tangata Tuatahi



# Foreword

Today people with learning disabilities are still living with the legacy of institutionalisation. The four people featured in this book, *A Place of Our Own* (and the documentary of the same name) show this to be true. People First New Zealand has created a great resource to motivate and inspire those who have experienced institutionalisation to tell their story before it is too late, and to educate the wider society about the realities of being institutionalised.

Graeme Parish is an amazing man and he has done a great job as the interviewer for this project. He undertook his role in a respectful manner and has a wonderful way of interacting with the people he interviews. He is a great leader for People First and an inspiration for many. As a person with a learning disability myself, I think it is fantastic that People First had this project fronted by a person with a learning disability, because nobody knows our world like we do.

The themes this book comments on – the difficulties of parenting, communication, institutionalisation and friendships and relationships are all part of the everyday experiences of people with learning disabilities.

Sharon's story shows the issues that people with learning disabilities must cope with to be parents. What she and her husband Stewart experienced, with people making assumptions about their parenting skills, shows that widespread discrimination still exists. People still think that because you have a disability, you can't cope as a parent – and this is not right. All people with disabilities should have the right to care for their own family, and we need to make sure these families get the right services and support.

Murray's experience of not being allowed to go to his mother's funeral was tragically common for people living in large institutions. While

staff may have thought they were protecting his feelings, he should have been allowed to grieve, and to have support and counselling to deal with his loss. His experience shows that there was often (and still can be) a lack of understanding about people with learning disabilities. I was happy to hear that since this project Murray has moved into a new living situation and is a lot happier.

Rolly's story shows the importance of everyone having a right to communicate. Just because people can't speak doesn't mean that they have nothing to say and should be ignored. Rolly's support staff are great examples of staff who have taken the time to understand the people they support. They listened to him when he talked about the bad things that had happened to him, and they responded by giving him the support that he needed to get through. Sadly, for many people with learning disability, when they disclose abuse, both historic and current, they do not get believed. Because of this, they do not get the right support to help them deal with what has happened to them, and they continue to live with the bad memories.

It's wonderful to see Kevin has written his life story on his computer, and is using it to educate others. Kevin has a great smile and sense of humour. His relationship with his girlfriend Charlotte reminds us that friends and relationships are very important parts of life. I hope Kevin's dream for the future of living with Charlotte comes true for him.

I too lived part of my life in a number of institutions: Campbell Park School, Lake Alice and Kimberley Centre. I was deeply affected by this experience, and have gone on to advocate for the closing of all institutions, not only in New Zealand but around the world. Though it's great that New Zealand closed its last large institution (Kimberley Centre), being institutionalised is not just about the buildings – the bricks and mortar – it's also about values, beliefs, actions and activities. It's about the way things are done, the decisions are that are made, who makes them and who has the control. In New Zealand we still need to work hard to ensure that people with disabilities do not continue to be institutionalised even though they live in community settings.

The most important and crucial thing is having support. It is support that enables us to do the everyday things in our lives. For some people

it may be a little support, and for others a lot more, but as Graeme says, 'It's all about having the "right" support.'

I greatly admired the people in *A Place of Our Own* as I know it takes a lot of courage to speak up about your personal experiences, particularly about those memories that are not so good. But in speaking up, hopefully others with a learning disability are inspired, and the wider community will be educated. These stories and others like them need to be told so that this part of our history – institutionalisation – is never forgotten or repeated.

Our experience is something that nobody can take away from us, and so is living with the legacy of institutionalisation.

— Robert Martin (MNZM)

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*Robert Martin has an intellectual disability and spent his childhood in institutions, experiencing the pain of separation from his family. Robert was the former National Self Advocacy Advisor for IHC, and has worked extensively in New Zealand and around the world. He now looks forward to young people with learning disabilities speaking out.*

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# Meet Graeme Parish

I was really proud to be the interviewer for *A Place of Our Own* – I got a lot out of the experience. I learnt how to communicate in different ways, and it was really interesting to hear so many different stories about trying to have an ordinary life.



I lived in an institution from about the age of eight or nine until I was about thirty-two. When I first went, there were eighteen children living in three six-bed dormitories. Over the years, the institution changed the way they did things. They went from the very large house, to smaller houses with about seven people in them, each with two staff.

I left the institution because I felt I was not getting the support that I needed. A staff member helped me talk to my family about what I wanted, and to find a flat for me. I was feeling frustrated and they recognised that I had outgrown what they could offer, and that I needed a flat of my own.

I now have more freedom, I look after my own garden, and choose what and when I eat. I get a few hours of support a week, and my support person helps me with the things I need to do. I belong to a few clubs and organisations, and enjoy getting out and about, going to movies and into town to do shopping. The hard part of living in my own flat is not having much money to pay the bills, and it seems to be getting harder. Because I do not have a job, I live on the invalid's benefit.

People First is a great part of my life. They have helped me to learn new skills and to be a part of the real world. I am now able to help others who have a learning disability. My People First work keeps me quite busy.

Everyone has a different story, and I think they all need to be told.

# The road trip begins

Hi. My name is Graeme Parish, and I have been chosen to go around the country on a small road trip, that will be really exciting for me. We will go and visit about five different people and we will see what life was like in the days of living in the institution compared to now, living in the community.

In the past disabled people lived in institutions like this.



Now they live in the community. We want to see how they are getting on.





## Meet Sharon Haig

I lived in Templeton in Christchurch for around twelve to eighteen months. Other than then I have lived in the community all my life. Nowadays I live in Rangiora, North Canterbury, with my husband Stewart, and our daughter April. I like it here. We have friendly neighbours and lots of support from friends and family – especially April's godmother who speaks up for us when we need it. We love our



house. There isn't anything I don't like about living here, but it would be good to have better home-help support – staff who can help in practical ways with things that are hard for us to do, and with April.

I love my three part-time cleaning jobs, and it's great to have the freedom to go out when we want to. I like being part of People First; being included in community groups, advising and helping others to speak up.

For fun I enjoy going to the movies, eating out, visiting friends, taking April to the park, watching DVDs and going shopping.

In the future I want to visit my family in Australia for a holiday, own our own home and open a jewellery shop one day. I also hope that April will have friends to play with soon, and that she will get a job and have lots of friends to go out with when she is older. April wants to train to be a doctor.



# Sharyn, Stewart and April at home

GRAEME: Sharyn used to live in the institution called Templeton  
Sharyn and Stewarts' daughter is April.

STEWART: This is a photo of our wedding. I had a moustache then.

SHARYN: Yes it was like kissing a prickly hedgehog!

STEWART: My brother knew Sharyn, and so I went round to her  
place on my motor bike. I used to have a motor-bike back then.

SHARYN: He was standing there, pulling his socks up looking very  
nervous, you know how males get!

APRIL: Excuse me, it was daddy!

GRAEME: Can you tell me about your first date?



SHARYN: We went to the Oxford for a meal. He said, 'Do you want to go for a meal?' and I said, 'Okay'. So we went there, and we talked.

GRAEME: Was it love at first sight?

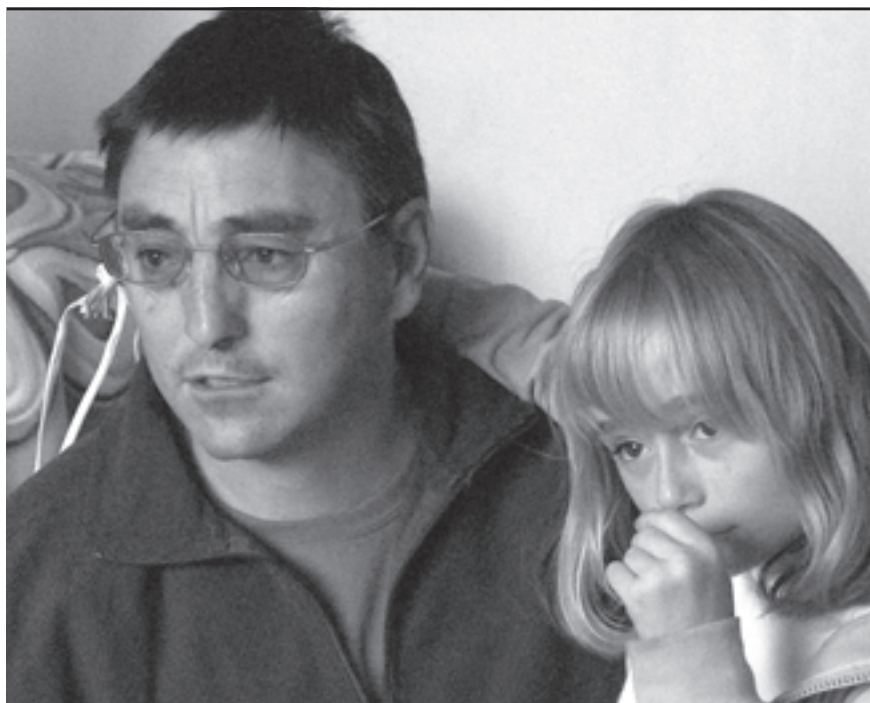
SHARYN: Yes it was. He said, 'Do you want to stay with me and be my wife?' I said, 'Pardon?!' I nearly fell off the motor-bike! It was quite funny.

STEWART: I asked her when we were going round to her place and we have been together ever since! April was two-and-a-half months premature when she was born.

STEWART: CYFS [Children, Youth and Family Service] wanted to come into our life. They wanted to take our child off us.

GRAEME: Why?

SHARYN: 'Cause I go to IHC, and they thought I wasn't capable and that. They stepped in and wanted to take April off us.



STEWART: Our caregiver, Sue, who is also April's godparent, helped us fight to keep April staying with us. They said the only way we could keep April was to go into care with someone else. Then we found out that they weren't allowed to do that to us – we had all the care in place. We moved into my mum's place, and April got a wee burn on her finger – we didn't know how it got there. We took her to the chemist to get a cream, and the chemist rang CYFS and we had another meeting with them – and we nearly lost April again. It shouldn't be like that for people with disability. April goes to school and gets teacher aide hours – four hours a day, and now only two hours a day – they knocked it back because there is not enough funding out there.

GRAEME: April is a real sweetie. I know they are struggling to get the right support at school. One of the big problems is lack of support and lack of money. These are two really major issues, and something needs to be done about it.



# Creating a place of our own as a family

For the past two decades disability researchers have focused considerable attention on parenting by adults with learning disabilities. Parenting is commonly recognised as one of the most rewarding, challenging roles that a person can choose to fulfill. It is also a highly respected social role. However, when a person with learning disabilities chooses to become a parent, rather than gaining respect, he or she can often be met with expressions of disbelief, mistrust and in some cases, overt opposition. While research has consistently reported that intellectual impairment does not inevitably cause a parent to provide inadequate care to his or her children, (Feldman, 1994; Tymchuk Yokota & Rahbar et al., 1990), parents with learning disabilities are often treated as if this was the case. Many experience discriminatory attitudes and formal legal opposition to their efforts to raise their children. Such resistance can be multifaceted, involving both their family, and professionals from health, child protection, family and disability services all working to undermine, rather than to enhance, parental competence. As a consequence, the extent to which children are removed from parents with learning disabilities is worryingly high, with current research reporting a child removal rate of 30–50 percent (Mirfin-Veitch et al, 1999), leading to the conclusion that this group of parents remains over-represented in child protection cases (McConnell & Llewellyn, 2000).

Sharyn and Stewart's story *A Place of Our Own* clearly illustrates the barriers that parents with learning disabilities face as they attempt to raise their children in New Zealand. Sharyn and Stewart's story is about family and the love that parents feel for their children. Unfortunately, Sharyn and Stewart's experience of parenting has been marred by the ever-present threat of their daughter April being taken from them. Sharyn and Stewart's honest account of this struggle provides an opportunity to challenge the long-held perception that parents with learning



disabilities make incompetent parents, and to begin a discussion about how we can best support families.

Sharyn and Stewart's relationship began very typically following their introduction to one another through a family member who thought that they 'would get along well'. On their first date they 'talked and talked' and 'have been together ever since'. The pride and security in their relationship was evident. However, similar to many other parents with learning disabilities, Sharyn's pregnancy and the subsequent birth of April signalled the start of a long struggle to prove themselves as parents. In the DVD *A Place of our Own*, April is a vivacious presence alongside her parents. Their mutual love and affection is clear in the way they interact with one another, and through the important family mementos such as photographs and artwork that are displayed throughout the house. This seemingly regular family environment serves to disguise the pain and anguish that Sharyn and Stewart have experienced as they have been forced to fight for April's continued presence within the family home and in their care.

— 20

Due to Sharyn's ill health, April was delivered prematurely. Her birth occurred over two months sooner than it should have, and both April and Sharyn had to spend a long time in hospital recovering. Photographs of a tiny April adorn the walls of the family home, signalling the importance of this time, and the relief that both mother and child survived this traumatic experience. But instead of being able to focus on April, Sharyn and Stewart had the additional worry of having to prove themselves competent to be April's parents. Stewart's poignant comment 'and then CYFS [Children, Young Person and Family Service] wanted to come into our life' resonates with the words of other parents whose need for support with their parenting is quickly cast as a care and protection issue (Booth & Booth, 2005). Many parents with learning disabilities who, like Sharyn and Stewart, have lived relatively independent lives, soon become overwhelmed with the level of surveillance and intrusion that accompanies their decision to have a child.

When asked why CYFS became involved with her family, Sharyn's reply highlighted two important points. First, the presumption that the

fact of a person's cognitive impairment is seen as 'reason enough' to instigate care and protection proceedings, and second, that removing a child is the best way to meet the support needs of families that include parents with learning disabilities. When Sharyn and Stewart embarked on the battle to retain their rights as parents, all the barriers that they were forced to face and overcome were underpinned by these two erroneous assumptions.

Research frequently reports that parents with learning disabilities require independent advocacy to navigate the complex and confusing child protection and legal systems that govern the decision about whether they can retain custody of their children (Booth & Booth, 1998). Sharyn and Stewart were fortunate to have a trusted support person who, in Stewart's words, 'helped us fight to keep April staying with us.' This person had provided support to Sharyn and Stewart in the past, knew them well and was prepared to advocate for them. Without her person, both Sharyn and Stewart may not have been able to satisfy child protection and other professionals that they were capable of providing April with a 'good enough' standard of care.

21 —

As previously mentioned, parents with learning disabilities sometimes do not get the opportunity to parent at all, if decisions are made regarding their competency prior to the birth of their child. In the case of Sharyn and Stewart, the professionals involved thought that the only way the couple could have the chance to parent was if 'they agreed, to go into care with someone else.' Some parents who do not or cannot meet this requirement, lose custody of their children. It is also evident that once parents with learning disabilities have had their children formally removed, family reunification is uncommon (Conder et al, 2008). That is, regardless of the reason for the child's removal, there is little commitment to supporting parents to learn the necessary skills to enable their child to return to the family home.

Because so many parents with learning disabilities do lose custody of their children, we often do not get to see the everyday realities of the demands of parenting. Sharyn and Stewart are open about the joys and the frustrations of parenting, demonstrating some of the strategies that



they, as a family, implemented in response to parenting issues. As do many parents, Sharyn and Stewart experienced difficulty in getting April organised for school in the mornings. Similar to many parents, they were advised to implement a reward system that clearly outlined the tasks that April needed to do to prepare for school. All members of the family could understand and work with this commonly used parenting strategy. This fact challenges the myth that parents with learning disabilities are unable to learn new skills that will lead to improved parenting.

The opportunity to develop increased confidence and competence as a parent is necessary to ensure that parents are able to demonstrate 'good enough' parenting over time. To achieve this, it is critical that parenting skills are taught in a context that is relevant to the parent(s), and in a way that is accessible to their particular learning style (Ely, Wilson & Phillips, 1998; Spencer, 1998). Generic parenting programmes that deliver abstract examples in 'classroom' environments do not adequately support parents with learning disabilities. However, such parents are frequently sent to such courses in the absence of specific programmes designed for their parenting needs.

Sharyn and Stewart's story provides an insight into some of the simple pleasures of parenting such as April and Stewart's shared responsibility for caring for the family's pet rabbit, a task they clearly enjoy doing together. A criticism often levelled at parents with learning disabilities is that their parenting is characterised by an inability to put their children first. Sharyn and Stewart expressed concern about the reduction in the amount of support April received at school. This demonstrated an awareness of their daughter's individual needs. Like most parents, they aspire to April reaching her full potential, recognising that the quality of her education is an important aspect of this.

Many parents with learning disabilities who have been able to retain custody and care of their children continue to feel as though they have only a tenuous grip on their family. Often, the level of scrutiny and surveillance they have had in relation to their parenting has been intense. Sometimes parents have been unaware that observations of their parenting have really been an assessment of their competence, and this

has led to child removal. People that parents have perceived to be supportive of their efforts to be 'good enough' are often required to report on their abilities. The content of such reports can, in some cases, contribute to decisions relating to child removal. It is with good reason that families who do manage to retain custody of their children are sometimes reluctant to 'let others in.' Sharyn and Stewart, who themselves encountered many attacks on their parenting, showed courage in allowing people an insight into their family through *A Place of Our Own*.

Parenting by people with a learning disability is a topic that attracts strong reactions and vigorous debate. Being a parent with learning disabilities in New Zealand is a vulnerable role. For many, the right to parent has been hard won. For others the dream of raising children has been unattainable due to an inability to reach that standard of 'good enough' parenting. While it is clear that parenting can be a realistic goal for some adults with learning disabilities, prejudicial attitudes and a lack of informed support combine to make it difficult to achieve.

A range of issues must be addressed to ensure that children are adequately cared for in safe and secure family environments, and that their parents with learning disabilities are well supported. Supporting these parents well is a complex task, and it is important to address parenting difficulties in a timely, formal and individualised manner. However, to effect real change in the parenting experiences of future generations of people with learning disabilities, it is essential to think more broadly about the barriers to parenting for this group. Prejudicial attitudes and an automatic presumption of incompetence will continue to impede the progress that adults with learning disabilities are able to make in this area. This position can be challenged by ensuring that young adults are educated to recognise and exercise their rights as citizens. Active citizenship and the ability to self-advocate creates the potential for people with learning disabilities to make informed decisions about their lives, including decisions relating to pregnancy and parenthood.

— Brigit Mirfin-Veitch

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*Brigit Mirfin-Veitch has been involved in research and education in the area of intellectual disability since 1994. Her doctoral research focused on family decision-making during the process of deinstitutionalisation. Over the past decade, Brigit has had a particular interest in and commitment to the support and advocacy needs of parents who have learning disabilities in New Zealand. Brigit is the Director of the Donald Beasley Institute and is an advisor to the People First New Zealand National Committee.*

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# Meet Murray Priest

As a child and young person, I was a state ward and I lived at a residential school and home in Oamaru. I have also lived at a Wellington boys home and at Ngawhatu Psychiatric Hospital in Nelson, and in residential homes in Nelson and Lower Hutt. I have lived in the community since I was eighteen, and I recently moved to Burwood, Christchurch. I live in a house with five flat-mates, supported by New Zealand Care.

I like lots of things about where I live now. It's like a hotel in California! The staff are wonderful – they treat me with respect. I have a big bedroom, comfortable bed and my own TV. My friends are free to visit, and I can come and go as I please.

My favourite thing about living in the community is having lots of friends and doing normal, everyday things. For fun, I like learning new skills, helping others in need, my People First work – I help out on the People First speaking-up course – watching the races on TV, white-baiting and fishing, dancing and night clubbing, and any kind of work.

My hopes and dreams for the future are to be happy, live life to the full, make people laugh, have good health and to go and see my mother and twin brother's graves.

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*Note: Since the filming and writing of the following interview with Murray, he has changed residential disability support providers.*

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# Murray at home

GRAEME: Murray lives in a rest home and is sixty-five. He has written a book about his life. Murray has lived in many different institutions. Murray spent time in an institution in Nelson called Ngawhatu. Murray's disabilities make it difficult to get around.

MURRAY: When I was young I had a very unhappy childhood because I was the black sheep of the family. I was the last one to get any attention because of my disability. I always got blamed for things for no reason at all.

GRAEME: How was it when your mother passed away?

MURRAY: For me it was very, very sad. I asked when she died and they told me, 'About a week ago'. I asked, 'Would I be able to go to the funeral?' They said, 'No'. I said, 'Why?' They said, 'Because you will be very upset.' That's why I said it was very sad. It still hurts me today. But she is up in heaven and I will see her soon.



GRAEME: So they didn't even ring and tell you when she died?

MURRAY: No, they didn't even bother to ring. Before I went to Ngawhatu the State asked me if I wanted to go to hospital. I thought I was going to an ordinary hospital. When I got there I thought this is very strange, this is not a hospital. I had never heard of institutions in my life. Well, when I got there I thought this is very strange, this is not a hospital, but anyway I moved in. The first thing they did was give me medication. I had never had medication in my life before. I asked the nurse, 'What is this medication for?' She said, 'Oh, it's to make you sleep'. And then one day they said they were going to do some treatment, they were going to use me as a guinea pig. I said, 'No way! I'm not going to be a guinea pig for nobody', 'cause I knew what they were going to do. You know what they did in those days, they were using that shock treatment and it was horrible.







GRAEME: I would like to talk to you about your experience of having a girlfriend

MURRAY: Yes I had a girlfriend. I bought her an engagement ring. But before I asked her I had to get permission. I wanted to get her parents' permission. But first I took her out to dinner at Cobb and Co, and I gave her roses, and I had the ring. After I went to ask her mum and she said, 'I'm afraid you can't get married'. I said, 'Why?' She said, 'I don't think you are suitable'.

GRAEME: What is it like where you live now in the rest home?

MURRAY: I don't want to comment about that.

GRAEME: Okay that is fair enough. Do the staff treat you fairly?

MURRAY: No comment.

GRAEME: What are your dreams for the future, Murray?

MURRAY: I want to dedicate my life to helping other people, who have more disability than I have. I get a lot of pleasure out of seeing people smiling.

GRAEME: How did you find the talk today?

MURRAY: Oh quite relaxing and I really enjoyed it

GRAEME: Well, you have a really amazing story.

# Institutionalisation in community

Murray's story serves to highlight how, although supported living is the objective of deinstitutionalisation, this has been very difficult for people to attain. Like Murray, people with disabilities continue to be highly vulnerable to institutionalisation either as they age, or should they encounter adversity in their lives.

There are many reasons why people with an learning disability continue to be at risk of ongoing institutionalisation in New Zealand. This chapter will look at the two principal reasons, as well as provide some guidance as to what characterises institutional behaviour and practices in the lives of vulnerable people.

## *The Changing Nature of Institutionalisation*

While we act as if institutionalisation is no longer present in New Zealand, in fact most of the services available to people with a learning disability continue to be very institutional in nature. We often equate the large groups and the buildings of places such as Ngawhatu with our understanding of what institutions are. However institutionalisation is much more insidious and pervasive than buildings. Institutionalisation is a way of thinking and acting around people who for some reason are seen by society to be 'less than' the general population.

When we look closely at how people with a learning disability are living in our communities you will generally find that:

- 1) They live in homes that are owned by a service agency.
- 2) They live with people to whom they are not related, whom they did not choose and have nothing in common with other than a disability, and who have been determined by a service agency.
- 3) They are supported by people employed by a service agency, people they did not choose, and often do not like or trust.
- 4) Access to transport and recreation is organised by the service agency and is with other people with disabilities.

- 5) Work and vocational options are provided by the service agency and are with other people with disabilities.
- 6) The service agency has direct access to their benefit income and determines what money will be made available for personal use.

This is what we would call having a life determined by paid arrangements outside one's own control. This situation arises because although we have convinced ourselves that we no longer have institutions, our predominant service model is one that provides custodial, segregated care. In other words 'institutional' care. All that has really changed are the numbers of people being supported, and the location in an individual community home. However, those organisations that now provide the policies, administration and oversight of these services are themselves larger than any previous institution ever was. In laying claim to having deinstitutionalised, we have done little more than exchange large hospitals for larger provider organisations, that continue to operate on the same set of understandings as the institutions which preceded them.

## The New Wave of Institutional Growth

The later part of the twentieth century, when the language of deinstitutionalisation was at its strongest, was also a time of the greatest expansion of institutions that has ever occurred in New Zealand. This was the beginning of the rapid growth and expansion of aged care facilities. The institution of the rest home is now a common feature of all New Zealand communities. This has had the effect of making institutionalisation itself more acceptable to people, and there is less and less outrage as more and more people find that there are few choices left open to them, other than to end their lives in an institution.

For people with disabilities this has resulted in an acceptance that it is all right for them, regardless of their age, to live in community institutions for the elderly. These aged-care facilities have all of the characteristics of the old institutions, with none of the associated outrage. Like Murray, for people with disabilities as they age, the likelihood

is high that their lives will have come full circle from institution to institution.

## The Characteristics of Institutions

The primary characteristic that leads to services becoming institutional is the assumption that 'professionals and the professional systems know best'. Michael Kendrick, international disability consultant, identified ten characteristics that define any service operating as an institution, in his workshop presentation 'How to Avoid Institutional Practise in Community Based Services'.

### 1) Custody Versus Development

Custody involves the notion of care and maintenance as the primary function of the service. Development, as the word implies, is about life-long growth and development. Institutionalisation happens when our systems err on the side of custody, or when the focus on 'keeping people safe' becomes more important than supporting people to grow and develop.

33 —

### 2) Standardisation Versus Individualisation

Standardisation involves establishing of a pattern into which individuals fit or have a place. Institutionalisation is always characterised by standardisation. Individualisation requires that there be variability from one person to another whatever the service arrangement. People themselves are not the same, so you cannot put them into the same mould. You cannot say 'it doesn't matter who the person is, we are going to do things the same way for every one'. Any system that fails to respond to diversity pushes people into institutions. The institutionalisation of people is associated with doing things the same way. In any process where you have prescription, you do not have discretion. In any process where you do not have discretion, you have institutionalisation. Without discretion you must standardise people's needs. Under such systems, individuals inevitably become sacrificed to standardisations of the system. If you lack a concern for the individual you will never have individualisation, only institutionalisation.

### 3) Rigidity Versus Flexibility

Institutionalisation is associated with rigidity or the reduction of human capacity. Rigidity occurs when people must conform to the system. Rigidity suggests that there is only one way.

### 4) Habitual Conduct Versus Mindfulness

Habitual conduct occurs when you fall into a consistent way of doing things. Mindfulness occurs when you reflect on and consider a range of ways of doing things. Mindfulness allows you to take on new thinking. Mindfulness can sometimes make you and others quite uncomfortable, as it challenges what exists. Without mindfulness, however, you cannot discover what might be possible or better. In services where mindfulness is encouraged, people are seldom content or happy with the quality of the service. Rather, such an approach encourages the climate of debate, and debate generates difference and dissention. People who are mindful will not be welcome in systems that are based on habit. Within habitual systems people make judgements and decisions without having an understanding of the basis of those judgements.

### 5) Prescription Versus Emergence

Prescription negates negotiation. Within a system based on prescription, people find it hard to approach any circumstance without a solution for that circumstance. Pre-existing answers are sought. Where pre-existing answers exist then so does institutional thinking. Mindfulness allows questions that lead to the emergence of solutions. Many people do not know how to start from scratch. They approach new situations with old or habitual solutions. People predominantly have a weak vision for what might be possible or for potential solutions.

### 6) Weak Vision Versus Imagining Better

Weak vision occurs when you are trapped by what you know, when the unfamiliar is something beyond your knowledge and experience. Institutionalisation is about people being trapped in solutions.

A key to avoiding institutionalisation is to be sensibly unrealistic. We must recognise that what is realistic today was unrealistic yesterday. To avoid institutionalisation we must avoid premature realism. Institutionalisation develops when you think that there is nothing better than what is known. When you believe yourself to be the best, then you have no reason to challenge yourself about what might be better.

### 7) Delegated Authority Versus No Authority

You cannot do better if you are forbidden to do it. When people who think outside the group or outside the status quo are marginalised, or forced out, then institutionalisation is present. Institutionalisation is also present when the person themselves and those people who are closest to them have the least authority. Bottom-up authority is one means by which one can reduce the risk of institutionalisation. If better options are to emerge, then there will be a need for people who are prepared to take the initiative, and it is essential that bureaucracies allow and encourage discretion. Institutionalisation develops when people are dispossessed of authority.

35

### 8) Service Segregation Versus Generic Resources

Service segregation gradually accentuates the difference between 'us and them', and therefore segregates people from each other. The use of generic resources tends to mean that people get to be treated more like other members of society. If people are included in the ordinary solutions of society then they are more likely to be treated well by that society. When you are expected or required to live with people of the same 'client status' then you have an institutional model. A notion of 'us and them' is the fuel that feeds institutionalisation.

### 9) Weak Social Inclusion Versus Strongly Supported Social Inclusion

If you want to reduce institutionalisation, then you have to create situations where people meet and get to know each other. Institutionalisation moves people outside of society so that no one really



gets to know them. Social inclusion cannot arise when the primary relationships in a person's life are people who are paid to be there. Many people who live in our current service systems continue to experience the primary impacts of institutionalisation, which include:

- 1) Social isolation
- 2) Limited or no personal relationships
- 3) Limited or no support networks
- 4) Limited or no personal resources.

Social rejection is a major component of institutionalisation. We need to actively create the ties that bind, otherwise the best we can possibly hope for is to break down service segregation, but we will not build social inclusion.

#### 10) Weak Initiative and Leadership Versus Strong Initiative and Leadership

If you want these things to change, you have to be prepared to take on the issues. Initiative and leadership is the antidote to institutionalisation.

— Lorna Sullivan

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*Lorna Sullivan is the Chief Executive of Standards Plus, a small, national agency in New Zealand working as a community resource to promoting innovation and change in the delivery of services and the development of community for disabled people and families. She is the co-ordinator of the International Initiative for Disability Initiative and the New Zealand representative for the Council for Quality and Leadership. Her particular areas of interest are in working alongside disabled people and their families to build services and supports that are genuinely relevant to their needs, and their individual pursuit for personally meaningful futures. She uses what she learns to support people with disabilities and their families, advocacy groups, service providers, and governments interested in working for genuine change.*

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# Meet Rolly Baker

I lived in Tokanui Hospital in the Waikato. I first went for respite days for a short time, and then I moved in on 13 June 1975, and moved out in September 1990. So I lived there for fifteen years.

I have lived in the community for twenty years in September. I've lived in Hamilton, Tauranga, Levin and Cambridge. At the moment I live in Cambridge, in the Waikato. I flat with three other people who have disabilities and New Zealand Care is my service provider. I like where I live, it is sweet here, and I like my flat-mates – but I would like to live with people with cerebral palsy, people I can talk with, not just staff – and in a bigger city, like Hamilton.

My favourite thing about living in the community is choice! I can choose what I do every day. I can choose what I eat, what I do, where I go and when to visit friends. I like to do lots of things for fun – driving around on my wedge – it is motorised, going to play the pokie machines and of course I have to have a drink. I also like swimming, horse races, and I don't do it at the moment but I do like horse riding and ten pin bowling.

In the future I want to manage my own life-service and to live with friends. I want Robyn and Irene to handle my finances, and help me train my support staff. I want to write about my life and living with cerebral palsy. My dream would be to have it printed to sell. I also want to go to university to learn.



# Rolly at home

ROLLY: Welcome to my home, I'm glad to see you.

GRAEME: Robyn, can you tell me how Rolly's communication book works?

ROBYN: Shall we explain that, Rolly?

ROBYN: First Rolly opens his mouth for yes, and closes it for no. The next thing Rolly is going to do is to choose a coloured page he is going to talk from. You have to look at Rolly's face to see if he opens his mouth for yes.

GRAEME: Blue, black yellow . . . I see Rolly wants to speak from the yellow page.

GRAEME: 1, 2, 3, 4, 5, 6, 7.

ROBYN: So we stopped at 2, then run your finger along to 7, and you can read what Rolly wants to say.

ROLLY: I am glad you are my friend.

ROBYN: So that is what he is saying to you, Graeme.





GRAEME: Oh that is very nice, Rolly.

ROLLY (through computer communication device): My name is Rolly Baker.

ROBYN: Rolly's eye controls the curser on the computer screen. This means that he can move the curser and tell us what he wants to say.

GRAEME: I am here to ask you some questions today about your life in the institution. Can you remember some of the good days living in Tokanui?

ROLLY: I went to the movies.

GRAEME: What other good memories do you have at Tokanui?

ROLLY: Nellie was a young nurse when I lived in Tokanui.

NELLIE: I knew Rolly when I worked at Tokanui, I'm now the clinical manager here. Rolly made a lot of friends at Tokanui, a lot of staff, and now that he lives back in Cambridge there are a lot of people who he knows.

GRAEME: What was bad about Tokanui? What actually happened to you there?

ROLLY: Sex, really bad.

GRAEME: Did you have sex with people at Tokanui, Rolly?

ROLLY: I don't like it.

GRAEME: Were you sexually assaulted there?

ROLLY: Very much.

GRAEME: Was there any police involvement about this?

ROLLY: After, and talking with Tania helped me.

NELLIE: Talking to Tania helped you grow and get over the abuse that happened to you at Tokanui, is that what you were trying to say?

ROLLY (opens his mouth to indicate): Yes.

GRAEME: How is life for you now in the community?



ROLLY: Really good.

GRAEME: Do you have a girlfriend now?

ROLLY: I'd rather not answer that question. It's personal.

GRAEME: That is okay, Rolly.

GRAEME: What would you like to do in the future? What are your big dreams that you have at the moment?

ROLLY: I would like to go and live in Hamilton with my flatmate from Cambridge, Johnny.

GRAEME: Thanks for letting us come and talk to you, Rolly. Your story is amazing.



# Listen to me: Effective communication in a place of our own

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I find not being able to speak the hardest thing to deal with. There is a tendency for people to think that if you cannot speak, you cannot understand, and that is rarely true. Sometimes I am treated as if I am not there. — *Kevin Thomson*

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Australia is criss-crossed by invisible paths that to Aborigines represent the ‘songlines’ of spirit-beings who strode across the continent calling out the name of everything that crossed their path – birds, animals, plants, rocks, waterholes. To Aborigines, the world was sung into existence (Chatwin, 1987). This idea, that we know what we have words for, is famously expressed by the philosopher Ludwig Wittgenstein. In the only book he published in his lifetime, Wittgenstein wrote: ‘the limits of my language mean the limits of my world’. But what then of people who don’t share the common vocabulary and whose stories often lie silent between the lines of a ready flow of words? (Roets et al., 2007)

In the stories captured in *A Place of Our Own*, we see how Rolly’s silence exposed him to sexual abuse and the darker corridors of institutional care. Sharon and Stewart, on the other hand, parent in a world where the integrity of their family depends on the advocacy of someone more articulate. And for Kevin, difficulty speaking meant that sometimes people treated him ‘as if [he] wasn’t there’.

Communication is elemental to human functioning. The ability to share meaning enables information to be transferred, providing the scaffolding upon which personal learning and development is built. It is the means by which we gain influence over our lives through the

expression of need and hope. But most importantly, shared discovery and disclosure is the language that binds people to one another. Effective communication is no longer considered an end in itself, but as a vehicle that has friendship, belonging and 'valued lives' as its destination (Bray, 2003; Butterfield, Arthur & Sigafos, 1995).

As a disability whose defining characteristic is learning delay, it is almost inevitable that people with learning disabilities experience some degree of communication difficulty (Bray, 2003). Lack of developmental potential was once seen as an immutable consequence of intellectual impairment. As a consequence, few of the current generation of adult New Zealanders with intellectual impairment have had an opportunity to benefit from early or ongoing assessment and communication intervention (Beukelman & Mirenda 1992; Seriere, Heeney & Rutlege, cited in Bray, 2003). In 2003, after a two-year consultation, the National Advisory Committee on Health and Disability reported being 'disturbed' by the systemic neglect of the developmental potential of this group of people and 'worried' by the lack of communication support available to New Zealand adult service users (NHC, 2003).

In the DVD, Kevin shows Graeme the Powerpoint presentation he made of his life story so far. With it, Kevin informs new staff that he went to Kimberley Centre as a five-and-a-half-year-old boy. The Kimberley Centre was one of a number of institutions in which thousands of New Zealanders like Sharon, Murray, Rolly and Kevin lived out the majority of their lives. Kevin reminds staff that Kimberley played a big role in his life, and interestingly, a lexicon of signs acts as a backdrop to the photo Kevin chose of himself as a younger man. For a number of decades, specialist institutions like Kimberley defined best practice for people with learning disabilities and a 'special school' was established there in 1959 (Hunt, 2000). Until 1988 the Kimberley 'special school' provided education to disabled children, many of whom had been turned away from community schools when they had been living at home with their families. The Kimberley that Kevin knew was, however, not the same for all residents, nor was it the same for the entire lifespan of the institution.

Despite New Zealand's long history of institutional care, almost no research has captured the experience of living behind the institution wall. One of the few exceptions was a five-year investigation of the impact that closing the Kimberley Centre had on the life quality of those who lived, worked and visited there. In that study, researchers found that of all the adaptive behaviours tested for, residents scored most poorly in language development. In this domain, approximately 93% of people with learning disabilities in wider New Zealand would have been expected to score better than their age peers at Kimberley Centre (Milner et al., 2008). Whilst it is not unreasonable to suggest that the number of residents at Kimberley with severe impairment would have been slightly higher, the context within which language development was expected to take place appeared to contribute most to residents' poor performance. In the institution, residents were engaged in relatively purposeless activity for 60% of their day. They stood, stared, wandered, slept or sat, ghosting through days on second-hand furniture that lined the dayroom walls. Busy staff fleetingly acknowledged residents as they passed, hurrying to keep the cadence of an unbending daily routine, or they regulated their attention sparingly so as not to disrupt the dayroom equilibrium. Kimberley staff initiated almost all interactions, and communication tended to be overwhelmingly instructional and littered with subtle cues that suppressed, rather than invited, ongoing dialogue. However, a pervasive acceptance by staff that many Kimberley residents had entered the institution speaking but would leave silent represented perhaps the most disquieting denials of personhood.

Beyond Kimberley, the acquisition of language competencies was one of a cluster of significant improvements in adaptive behaviour to emerge. In the new community houses, Kimberley residents and support staff met as strangers. Support practice occurred within an 'ethic of discovery,' as staff worked hard to build relationships, discover personal preferences and find the limits of individual competence (Milner et al., 2008). Unearthing buried fragments of communication was a powerful reinforcer to new staff, and like Templeton families before them (Mirfin-Veitch, 2005) the recovery of language was taken

by Kimberley families as an important symbol of the return of the loved family member (Milner et al.). Although residents were, on average, spoken to twice as often in community-based settings, communication continued to be fleeting, instructive, inquisitive and initiated by staff, consistent with findings reported in similar international studies (Hile & Walbran, 1991; McConkey, Morris & Purcell, 1999). By the end of the first year, the 'ethic of discovery' that residents were met by had been replaced by support practices that valued knowing, anticipating and managing. Because of this, the acquisition of language and other adaptive competencies stalled.

The importance of the communication environment, including the vital role staff play in facilitating communication and the development of communicative skill, is recognised in New Zealand law. Right 5 of the Code of Health and Disability Services Consumers' Rights Regulation 1996 requires disability providers to respect service users' right to effective communication.

One way to respond to the challenge of respecting the right to effective communication for people with a learning disability is to think of it as a problem of externalities. Through the application of sufficient technology, skill and resources, it becomes possible to remediate individual communication difficulties. The difference the presence or absence of aids to communication can make to life quality is made plain in *A Place of Our Own*. Rolly, for example, finds words enough to free himself from what Jean-Dominique Bauby described as the 'diving bell' of a body that refuses to listen to instruction (Bauby, 1997) with the assistance of augmentative and alternative communication devices and skilled staff. Kevin, on the other hand, was forced to make himself present with much simpler tools, and most people with a learning disability live a lifetime without access to skilled assessment or intervention.

None of the closure programs that would eventually remove the total institution from the New Zealand support landscape acknowledged the need of former residents to have access to appropriate communication assessment and intervention (Bray, 2003). We know too that there is

little point helping communication skills unless potential communication partners are also trained in ways that make them responsive and affirming of communicative attempts (Butterfield, Arthur & Sigafos, 1995). Despite the fact that a number of studies have demonstrated the effectiveness of training staff to promote language competence (McLeod, Houston, & Seyfort, 1995; Pennington et al, 2005; Rogers et al, 2000), no government funding currently exists to train New Zealand staff to incorporate practices that enhance effective communication in their day-to-day support (NHC, 2003).

As a consequence, many people with disabilities remain silent. After intensive observation of four non-verbal adults, researcher Trevor McDonald found the New Zealand service users he followed used a wide range of strategies to communicate, but that most of the opportunities they created for interaction passed unnoticed (McDonald, 1997). Other researchers have reported widespread failure by staff to recognise behaviour as communication (Sigafos et al., 1994; Houghton, Bronicki & Guess, 1987; both cited in Butterfield, Arthur & Sigafos, 1995). ‘You need to keep looking at Rolly,’ Robyn gently insists – but it is more than attention on which Rolly depends. At some point, attentiveness had been accompanied by an expectation that Rolly’s behaviour was communicative, and the belief that his vocalisations, gaze, and the opening and closing of his mouth offered an alphabet upon which Rolly could construct the words he needed to tell the story of his life. Too often, the absence of words is interpreted as a lack of comprehension (Booth & Booth, 1996). Without the aid of someone to interpret, Kevin tells us his lived experience included a tendency for people to assume he could not understand, didn’t have a grasp of English or, he chuckled ‘was a bit thick.’

The vision at the heart of the New Zealand Disability Strategy is of transforming New Zealand into a more inclusive society. We will know when we have arrived, the strategy tells us, when all people are able to participate in their community in ways that lead them to conclude they are experiencing valued lives (Minister for Disability Issues, 2001). Such a vision is not achievable unless all citizens are able to be heard,

and have a voice that contributes to the way we collectively understand ourselves. For people to be 'of' as well as 'in' place in New Zealand communities.

In recent years, attempts to define effective communication have changed dramatically. Whereas assessing and remediating individual deficit had been the focus of traditional approaches to communication intervention, the best practice currently emphasises improving aspects of relationships as the primary goal – in particular, enabling participatory, socially valued, image-enhancing social membership (Ferguson, 1994; cited in Butterfield, Arthur & Sigafos, 1995).

This re-conceptualisation of communication acknowledges the critical role the relational context to communication plays both to development of language competence and to the dynamic, two-way process of finding ways to share meaning. Butterfield, Arthur & Sigafos describe communication, not as an end in itself, but as the vehicle that had membership as its destination. They also assert that research has consistently shown effective communication is best achieved when interaction between both partners is characterised by genuine interest, sensitivity, adaption, reciprocity and respectful turn-taking. Given that these are also important markers of social closeness, it would appear, therefore, that the vehicle and the destination may simply be opposite sides of the same coin.

The more difficult response to respecting people with learning disabilities' right to effective communication may be to see the solution as lying within ourselves. Reid & Bray (1998) make the point that, for people with learning disabilities, being 'in' place often includes the normality of discrimination, intolerance and more subtle forms of personal exclusion. Communication that lacks the conventions and rhythms of everyday language locate people with learning disabilities beyond the common vocabulary of community. It exposes them to behaviour that Edward Hall (2004) suggests reflects a deeply embedded sense of difference. If relationships are the cornerstones to effective communication, people with learning disabilities will remain absent

from conversations at the heart of community for as long as the type of social ‘othering’ that left Murray struggling to maintain self-esteem remains uncontested:

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I was the black sheep of the family. I was the last one to get any attention because of my disability. I always got blamed for things for no reason at all. — *Murray Priest*

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Tim and Wendy Booth make the point that although ‘inarticulateness’ might originate in restricted language skills, it is usually overlaid by other factors, including lack of self-esteem, learned habits of compliance, social isolation, loneliness and the experience of oppression (Booth & Booth, 1996). The experiences are familiar to the men and women who entered Kimberley speaking but left silent, or who currently wait to be noticed and engaged as equals in community-based settings. For people like Sharon, Murray, Rolly and Kevin to sing themselves into existence, those who have plenty of words need to step into their lives as friends, willing to fill the space where words would ordinarily be. One of the slides Kevin uses to speak to staff on his behalf is titled ‘Listen to me’. To uphold the legal right of people with learning disabilities to effective communication, we need to follow his instruction and listen attentively and respectfully to the wisdom embedded in stories like those captured in *A Place of Our Own*. Stories that might otherwise have fallen beyond the limits of our knowing.

— Paul Milner



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*After a short tenure as a teaching fellow in the Geography Department at the University of Otago, Paul spent ten years working alongside people with learning disabilities in a variety of support and service leadership roles. He joined the research team at the Donald Beasley Institute in 2003 where he is currently a senior researcher. Paul has a commitment to capturing the theorising of people with intellectual disability, especially as it relates to alternative imaginings of belonging in New Zealand communities and people's 'quality of life' in and out of disability support services. Beyond his research, Paul continues to provide service mentoring and has had an ongoing commitment to supporting the collective advocacy of Dunedin People First.*

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# Meet Kevin Thomson

53 —

I lived at Kimberley, in Levin, for thirty-five years – I was six when I first moved there. When I moved out, I went to Rotorua first, then to Whakatane in 2007. I like living here, but I really would like to move in with my girlfriend, Charlotte. My favourite thing about living in the community is having choices. I like to spend time with Charlotte. I also like to visit with people from Kimberley, but due to logistics it doesn't happen as often as I would like. In the future I would like to live with Charlotte, advance my career as a disability educator and go tandem skydiving.

# Kevin at home

GRAEME: We are going to see Kevin. Kevin and Rolly are mates. Kevin has cerebral palsy too. Kevin has made a story of his life and put it on Powerpoint.

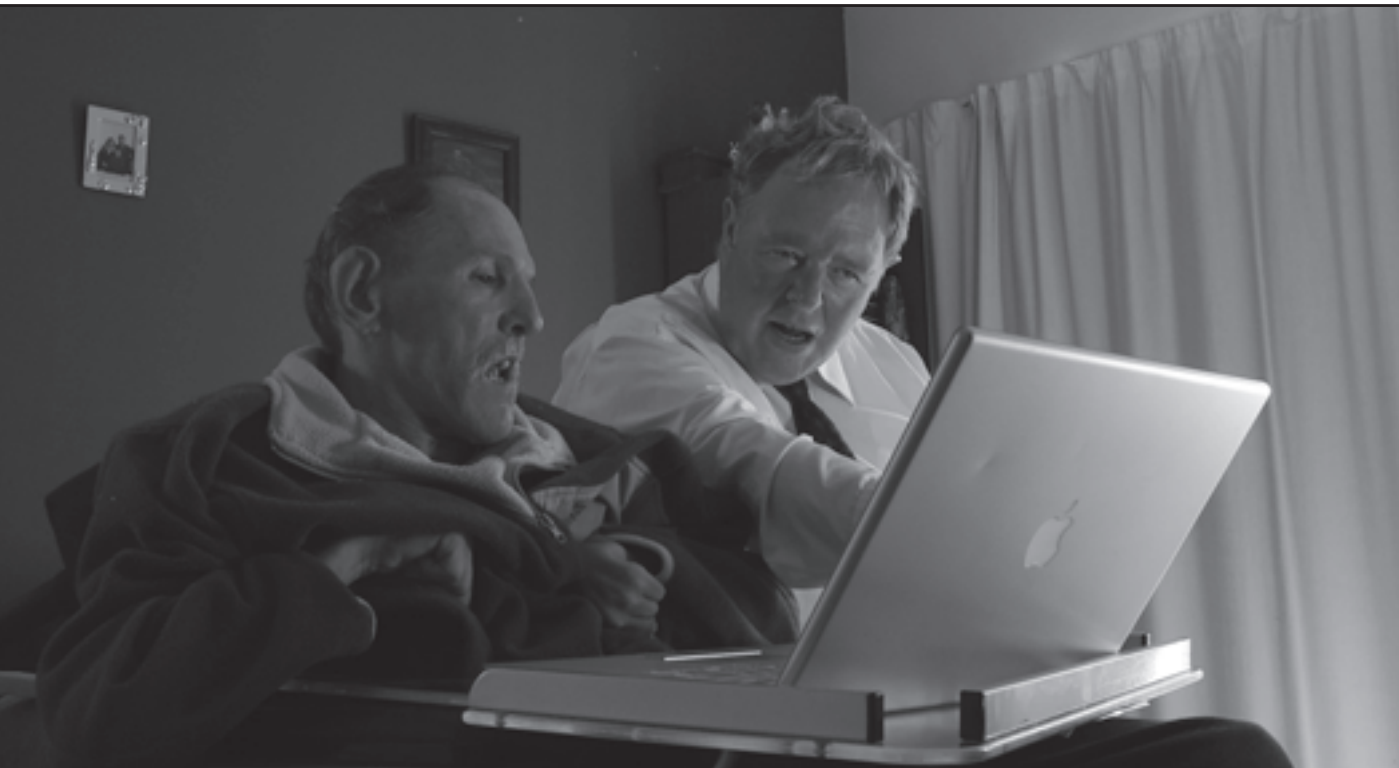
GRAEME: Is this your slide show, Kevin?

KEVIN: Yes.

GRAEME: You are using this for teaching now, aren't you?

KEVIN: Yes.

KEVIN: I was born fifty-one years ago in the Wairarapa. I lived at home with my family until I was five-and-a-half years old. I then went to live in Kimberley. It was a residential hospital where people with intellectual and/or physical disability went to live. Kimberley was my home for the next thirty-five years, so it was a big part of my life.





GRAEME: Kevin spends a lot of time with his girlfriend Charlotte. Charlotte lives close by.

KEVIN: I find not being able to speak the hardest thing to deal with. There is a tendency for people to think that if you cannot speak, you cannot understand, and that is rarely true. Sometimes I am treated as if I am not there, can't hear, don't understand English or am a bit thick. Sometimes people are too embarrassed to speak to me and that is a shame. Well, look at what they are missing out on!



## Kevin and Rolly reunite

GRAEME: We have a big surprise for Kevin. Rolly has come down from Cambridge to see his old friend. We know that both guys like spicy food, so we took them out for a curry and a beer.

ROLLY: Hello Kevin how are you?

ROLLY: Can I get a big strong drink?

CHARLOTTE: Does that sound like you Kev?!

ROLLY: The doctor says that the wine helps with the cerebral palsy!



# 'No man is an island': Finding a place in friendships and relationships

Most people would agree that their life is enhanced by the quality and quantity of relationships that they are able to enjoy. Unfortunately, many people with learning disabilities have little opportunity to develop relationships, and as a consequence, their lives can be lonely and isolated. It is also clear that other people often have different expectations for people with learning disabilities with regard to their relationships with families, friends and partners. Relationships that are commonly expected, and accepted, for others are frequently challenged, ignored or overlooked in the case of people with learning disabilities. All the contributors to *A Place of Our Own* tell stories with strong themes about the importance of relationships to people with learning disabilities.

57 —

## Friendships

Friendship and having friends is a critical component of being human (Staub, 1998). However, many people with learning disabilities continue to lead impoverished lives in terms of day-to-day friendships and relationships (Richardson & Ritchie, 1989). While people with learning disabilities desperately want friends, they often have only limited or fleeting opportunities to meet people with whom they could potentially develop relationships.

In the past, institutionalisation often resulted in people being isolated from their families, friends and communities. People with learning disabilities turned to their peers and to institution staff for friendship and support in such environments. While personal accounts and research tell of the atrocities that were perpetrated on people with learning disabilities within institutional settings, it is important to acknowledge that many of the relationships that were forged in these

settings were positive and sustaining. Unfortunately, for many of those previously institutionalised, these important relationships are lost as people disperse to new homes in the wider community. In *A Place of Our Own* we see that these 'interrupted' friendships remain important to people, and they continue to express the desire to reconnect with old friends. The joy and excitement on the faces of both Rolly and Kevin when they met after a long time apart leaves no doubt about the emotional bond that was shared by these two men. That Rolly and Kevin had the opportunity to meet at all was due to the skill and goodwill of individual support staff who knew each of the men, and who recognised the importance and depth of their relationship.

Over twenty years ago, Kennedy, Horner and Newton (1989) commented: 'Social contacts are at the heart of community integration. Without repeated social contacts an individual has little chance of gaining acceptance by members of a community.' This comment continues to hold true, and highlights the fact that people with learning disabilities often require active support to develop and maintain relationships. They need regular opportunities to meet people and the skills to turn superficial contacts into real relationships. Unfortunately, in the delivery of day-to-day 'care', support with interpersonal skills and relationships can be frequently overlooked. In 2003 the National Health Committee released a report titled *To Have an Ordinary Life*. This report recommended that 'recognition be given to the importance of adult relationships in the lives of adults with intellectual disability', with the Ministers of Health and Disability Issues directing the Ministry of Health to 'include active support to make and maintain reciprocal adult relationships as an essential component of all needs assessments, service specification and purchasing arrangements.' (NHC, 2003). Assisting people to develop the personal capacity to create and maintain relationships is a complex task, and one that support workers may require help to achieve.

The issue of 'paid friends' also needs to be acknowledged. In the absence of other 'unpaid' friends, support staff who acknowledge and respond to the emotional needs of people with learning disabilities

come to be seen as friends by the people they support. Many people with learning disabilities consider that the relationships they have with paid support workers are friendships. This is unsurprising, given that these people may be the only consistent presence (other than family) in their lives. Sometimes paid support workers have been part of an individual's daily life for very long periods of time. Rolly's story shows just how important his support workers were to him. Robyn's commitment to enabling Rolly to communicate with those around him is tremendous, as she takes every opportunity to teach others how to use Rolly's communication system. The documentary shows her teaching the Indian restaurant staff how to converse with Rolly – a tremendous example of how getting to know someone just a little can challenge previously held perceptions. Rolly also made a point of explaining the special role that Nellie had in his life. Now Clinical Manager of the service that provides Rolly's support, Nellie had been a young nurse in the institution at Tokanui at the same time that Rolly resided there. Rolly and Nellie had a shared history of institutional life, and deinstitutionalisation. Nellie's presence in Rolly's life meant his history, and personal identity, can be more easily shared with others that come into Rolly's world in the future, potentially making it easier for people to get to know him. Marquis & Jackson (2000, pp. 421–422) offered the following statement that provides valuable insight into the way we need to view friendships between people with learning disabilities and the men and woman who are paid to support them:

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Creation of a social world through relationships with others in any life situation has potential to fulfil the basic need to relate, act out personal drama and to find a capacity to develop resilience and meaning in life. Although not a substitute for natural friendships, validating relationships between people living and working in services have potential to provide people with disabilities with a sense of attachment, emotional integration and stability, reinforcement of worth, and the development of confidence in entering other relationships.

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## Relationships with family

*A Place of Our Own* also sheds light on the diverse relationships that people with learning disabilities have with their families. Family relationships are often the most consistent and stable relationships they may experience throughout their lifetime. Families frequently play an active and ongoing role in the decision-making that affects the lives of people with learning disabilities (Mirfin-Veitch, 2003). Depending on their views and perceptions of their family member, such decisions may inhibit or enhance the relational opportunities that their relatives are able to enjoy. Murray's story highlights the ambivalence that can accompany family relations, highlighting both the positive and the negative impact that family can have on the lives of people with learning disabilities. Murray's affection for his sister was clearly apparent in the early stages of his story as he showed the interviewer pictures of warplanes his sister had sent him. That she acknowledged and supported his interest, appeared to make Murray feel valued by her. This was in contrast to the understanding of his role in the family that Murray later shared. Murray said: 'I was the black sheep of the family . . . I always got blamed for things for no reason at all.' He saw his disability as the reason for this. Murray is clearly emotional when he speaks of hearing about his mother's death a week after it occurred, and of how he was not given the opportunity to attend her funeral. Other people had made the decision that he should not go to his mother's funeral because, in his words, 'I would be too upset.' The notion that people with learning disabilities should be protected from the reality of death, and prevented from grieving, is misguided and directly contradicts much of what mental health professionals would advocate in terms of bereavement. Murray appears to have found his own way to manage the impact of being denied an opportunity to publically grieve his mother's death – by holding to the belief that he would be reunited with her upon his own death.

## Relationships with partners

While many people with learning disabilities aspire to having a loving partnership, all too commonly this remains an unfulfilled ambition. In

*A Place of Our Own*, Sharyn and Stewart prove that it is possible for adults with learning disabilities to meet, fall in love and marry, showing the photographs of their wedding day with pride. Kevin and his girlfriend Charlotte supported each other through the filming of *A Place of Our Own* showing that Kevin's difficulty with verbal communication did not preclude him from experiencing a loving partnership. The stories of these two couples contrast with Murray's quest to establish a committed relationship. Murray's ability to experience married life was inhibited by family – though in this example not his own. Murray talks of having a girlfriend that he proposed to; while his girlfriend accepted his proposal, they were prevented from marrying by her family. Murray's perception of the situation was that his girlfriend's family did not think he was good enough for her. As previously mentioned, family can provide the most meaningful and powerful relationships in a person's life. It is important, however to recognise people with learning disabilities as adults who may need support to make decisions, but who also may have their lives limited by excessive control.

## Conclusion

The importance that people with learning disabilities place on friendships reinforces the need to pay attention to the relational quality of life that people are able to enjoy. *A Place of Our Own* also challenges us to think beyond where people live to how people live. While institutional life was undeniably difficult for many people, some of the relationships that people forged in those institutional settings were positive and affirming. Taking the time to learn about those friendships, and to support them to continue, is a critical aspect of honouring people's personal histories. It is also important to question whether the current living environments of people with learning disabilities afford them with real opportunities to make friends. Recent research has explored the experience of loneliness in the lives of adults with learning disabilities (Stancliffe et al, 2007). The research found that one-third of all (1002) participants felt lonely some of the time, while one-sixth reported that they frequently felt lonely. Interestingly, the people who

were most lonely lived in community-based services that accommodated between 715 people in one home, while people living alone or with only a small number of other people reported less loneliness. This research highlights that simply living with other people does not automatically ensure that a person feels connected to them. Stancliffe et al. identified that people who had ongoing contact with family and friends, and who liked where they lived, were less lonely. Being afraid at home, or in their local community, resulted in people feeling more lonely. The dominant model of service delivery in the New Zealand context is the five-to-six bed group home. Often the people living in such services have had little choice about who they are living with and frequently express a desire to live alone, or with other people of their choosing.

People with learning disabilities have been, for some time, telling us *how* they want to live – with people they like, and in environments that allow them personal autonomy and the opportunity to build meaningful and long-lasting relationships. It is time to listen.

— Brigit Mirfin-Veitch

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# People First New Zealand Inc.

People First is a self-advocacy organisation for people with learning disabilities run by people with learning disabilities. People First New Zealand is part of an international self-advocacy movement, and there are People First groups in Canada, the United States, England, Australia and several other countries. People First was set up in New Zealand in the 1980s and has been an independent Incorporated Society for over six years.

People First uses the term 'learning disability' rather than 'intellectual disability' as members think it is more respectful. To be a member of People First you must be a person with a learning disability, and be over eighteen years of age.

People First members help each other to:

- Be respected

- Be listened to

- Learn about rights and responsibilities

- Speak out

- Have our ideas heard by local and national government, councils and service providers

- Teach people in the community about valuing people with disabilities

People First New Zealand provides information and advice about rights and supports for people with learning disabilities. It also runs courses for people with learning disabilities and delivers educational presentations to the wider community.

To find out about joining People First, or to get more information about learning disabilities:

Phone: 0800 20 60 70, or

email: [mail@peoplefirst.org.nz](mailto:mail@peoplefirst.org.nz)

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