



“I don't want to miss a thing”

STORIES OF REGENERATING LIVES,
FROM PEOPLE SUPPORTED BY THE THISTLE
FOUNDATION IN RENFREW

“I don’t want to miss a thing”

STORIES OF REGENERATING LIVES,
FROM PEOPLE SUPPORTED BY THE THISTLE
FOUNDATION IN RENFREW

compiled and edited
by Julia Fitzpatrick
with Jaynie Mitchell

in  **Control**

First published October 2006
ISBN 0-9554119-0-4
978-0-9554119-0-8

in  **Control** in Control Publications
PO Box 45377
London
SE14 5JU

Lorraine Brown and Jim Carmichael passed away in May 2006,
having approved the final drafts of their stories but before this
book was printed. This book is dedicated to them.

FOREWORD

The Thistle Foundation is an unusual and wonderful organisation and these stories represent some of its many virtues well. Two things in particular stand out.

The first is commitment. Behind these stories lies the commitment of The Thistle Foundation to ensure that those people who it felt a responsibility towards were not left stranded in the social care system. The Thistle Foundation is not just a service provider, commissioned by a local authority, it is an organisation driven by a strong sense of its own ethical responsibilities.

Second The Thistle Foundation continues to show us the true meaning of support. The Thistle Foundation knows that doing its job well is about helping people lead the kinds of life they want to live. The Thistle Foundation's job is not to care but to liberate.

But nothing lets us see these qualities better than the real life stories that are told in this book. Stories which show us again and again how much the whole world has to benefit from the active contribution of disabled people.

I am very pleased that **in Control** was given the chance to publish this book and I hope it will help people see what can be achieved when we focus our attention on giving people back power over their own lives and helping people set out on the road that makes sense for them. In Hasidism it is said that "God created people because God loves stories." Let us be inspired by these stories to work to ensure that everyone has a story worth telling and that no one is left with their story untold.

Simon Duffy
National Director
in Control

CONTENTS

Introduction	7
Contexts and catalysts.....	11
The stories.....	15
Beneath and beyond	59
References and acknowledgements	69

INTRODUCTION

Between December 2000 and June 2001, 14 people began new lives - a regeneration process of discovery and rediscovery. They moved from institutional care for people with learning difficulties and physical disabilities to their own brand new homes in two ordinary neighbourhoods in Renfrew, Scotland. They had spent between 10 and 65 years in different institutional environments - an average of 28 years each - and a combined total of 339 years in care. All, in unique ways, needed and need support to live full and included lives, to participate in and contribute to their community and to achieve their potential.

The power of individuals to change their own or other's lives can inspire and move us. Occasionally when watching the news or reading a magazine article we can be in awe of personal achievements presented to us. Yet in day-to-day life we seldom stop to reflect on and celebrate the quiet yet transformational changes that may be happening around us.

This project draws together eleven personal stories, giving a voice to the individuals, and those who care about them, to tell their account of life now and life before they moved here. Over the last five years, they have transformed their lives and those of the people around them. These are astonishing tales of resilience, hope and ambition.

As one person reflected, life for them is becoming "mostly good and getting even better". People forget, and sometimes want to forget, what was described by another as "miserable times" in institutional care. When you are getting on with enjoying today and planning tomorrow, reflecting on what has changed and how this has happened is not easy. These stories are their, and our, history and record for the future.

They offer insights about the nature and quality of support needed to make possible these powerful improvements. These may be useful to those considering ways in which they can be supported, and to those providing support.

THE STORY COLLECTING PROCESS

Each story is narrated as far as possible from the individual's perspective. We invited everyone supported by The Thistle Foundation in Renfrew to contribute to the project and eleven were keen to tell their story, including one couple. We met and interviewed people individually. Some had asked a support worker or a family member to help with telling their story. People spoke in words, with their own previous writings, photographs and video or DVD recordings. Some people had no verbal communication and family members sat alongside them using photographs or DVD to tell their story. Others had limited speech and the interview style was adapted using closed questions and non-verbal communication, together with the assistance of family or support workers to flesh out the story.

We compiled the interviews into written stories and then returned them to each person to check if they were happy with how their story read and to make any necessary corrections or amendments.

To complement the stories, the first chapter provides brief background on the context and catalysts for the housing and support service development within Renfrew. The final chapter reflects on some themes the stories have in common, highlighting what needs to be sustained and developed to secure the achievements of everyone involved.

This book is not intended as a research report nor designed to give academic analysis. We heard and recorded individual stories without seeking objective corroboration or clarification. Rather the stories in themselves are a means of communicating and sharing knowledge and experience. Storytelling is argued to be 'high in social presence' (Sinclair, 2005). These stories remind us of the contribution that was missing from our communities for so long.

“We all know instinctively that nothing can ever give us ‘the whole picture’, that the total complexity of reality will always evade us, however hard we struggle for ‘truth’, but oral testimony is the individual’s personal truth and as such its subjective contribution to history is vital and illuminating. The way each of us tells our story reflects the way in which memories are shaped and gives meaning to how we see ourselves in the world.”

Jenny Simmons, 2000

CHANGING LIVES

The same as you? A review of services for people with learning disabilities (Scottish Executive, 2000) acknowledges the rights of people with learning disabilities to have a full life and to be full citizens - included and at the centre of decision making.

In Changing Lives: The Report of the 21st Century Social Work Review, (Scottish Executive, 2006) it is clear that traditional ways of organising services and paying for them are not sustainable and that there needs to be transformational change to “engage people as active participants, delivering accessible responsive services of the highest quality and promoting wellbeing.”

These stories provide evidence for the positive impact of personalisation, with individually tailored support services extending choice and transferring control to the person. They illustrate that this is both difficult and possible. As importantly, the stories remind us that regeneration is a living, organic process and that our history of inclusion is young and fragile. These changing lives have just begun.

CONTEXT AND CATALYSTS

The Thistle Foundation was established in 1944 to enable disabled veterans to live with their families and receive medical support. This was a radical departure from a dominant model of hospital-based accommodation. It built 103 houses and a residential care home on a single site on the outskirts of Edinburgh. Over the years, it extended to provide services to people with disabilities who had no service connection. In 1993 it completed a new residential care home in Renfrew - Blythswood House - to provide accommodation and care for 20 people (all wheelchair users). People moved there from all over Strathclyde, then a single regional authority.

THE CLOSURE OF BLYTHSWOOD HOUSE

Blythswood House was completed at a time when the expectations and aspirations of disabled people were changing. Policy changes at local authority level, following Sir Roy Griffith's report (1988), introduced the concept of 'care in the community' as a preferred option to institutional living. Strathclyde region divided into 5 local authorities, who were less inclined to purchase care outside their area. Empty places at Blythswood meant that The Thistle Foundation subsidised the continued running of the home and this was not financially viable. The Thistle Foundation was changing too and providing residential care was no longer consistent with its vision of maximising supported independent living. These factors prompted a decision to close the home in 1998.

David Crawford, then Head of Operations, now Renfrewshire Council's Director of Social Work, recalled: "There was an irony that the staff were actually very good at helping people connect to community services, at advocating

and helping people to move out, but it left them with vacancies and Renfrewshire wasn't big enough to fill all 20 places."

Managing the closure of an institution is never easy, and often controversial. Margaret McMahon, The Thistle Foundation's Support Service Manager (Operations) reflected: "We closed it with a vision, but not an overall plan. There was loads of planning at an individual level but this didn't link into the timing for closing the home, so every person left Blythswood with their 'ideal home' plan under their arm - but no-one moved to their own home. They went to Edinburgh, Glasgow, Irvine... Blythswood was closed and the people were scattered, but we knew they weren't where they wanted to be and we had made a commitment to them."

Renfrewshire Council's Social Work Department had supported the decision to close the home and worked closely with The Thistle Foundation to negotiate the arrangements with residents and their families. This involved assisting other local authorities, making interim residential care arrangements outwith the area (for people who really wanted to be supported in their own homes), and sharing The Thistle Foundation's commitment to this long-term goal.

INDIVIDUAL HOMES, ORDINARY NEIGHBOURHOODS

The next step was considering practical issues - many of the people used wheelchairs or their needs were such that purpose built or adapted accommodation was required. Two Housing Associations (Horizon and Margaret Blackwood) with particular expertise in designing housing for disabled people happened to have development sites in Renfrew - at Clark Street and High Mair. With the participation of Communities Scotland, their development plans were brought forward to create housing tailored to the needs of the individual and set within integrated housing developments, including housing for rent and sale. Assistive technology was included in each new home, programmed to individual needs to enhance the environment, safety and independence.

NO LONGER JUST ABOUT BLYTHSWOOD

There was a gap in time between closing Blythswood and creating plans that would offer a preferred alternative. Having settled elsewhere, some residents did not want to move back to Renfrew and, during this time, other needs were also emerging:

- Renfrewshire Council was in the process of developing strategies and resources to meet the demands of people moving out of Merchiston Hospital, near Renfrew, as part of its planned retraction.
- Other unsuitable residential homes had been earmarked for closure, in particular Westlands in Erskine, bringing a need for more independent wheelchair accessible housing.
- Young disabled people in the care of Renfrewshire Council were reaching the age where they needed to leave residential schools and institutions. As David Crawford now comments: “There is still major uncertainty for young people and their families about the future and where they will go.”

PUSHING THE BOUNDARIES

David Crawford pointed out that the processes for achieving this transition from institutional care to care in the community were not new. Rather “the issue here was how far could you push the boundaries in terms of being able to meet the needs of very dependent people in their own homes. The integration of the clusters of housing into the rest of the community was so different and it’s a beautiful example of how it can work. It pushed those boundaries and The Thistle Foundation was a strong advocate for people to push them...and it changed where the boundaries are.”

He acknowledged that to some extent the closure of Blythswood drove the Council to consider alternative ways in which people could be supported: “People want long term security, people want settled lives. They have far greater control in their own homes, in their own tenancies, with individualised supports and personalised services.”

The following stories echo Peter Peacock's words in his Ministerial Response to Changing Lives: Report of the 21st Century Social Work Review (2006): "Personalisation is not a new trend... However it is clear that the principle of personalisation needs increasingly to be the philosophy on which social work services are founded."

VINCE” I don’t want to miss a thing”

The name is ‘Hayes’, Vince Hayes. I’m a great film buff. I’ll amaze you with my memory for film and song titles and scenes, but I forget day-to-day things, so I rely on support staff. ‘Independence Day’ for me was in December 2000. I don’t forget that - it meant too much. I was 37 years old when I got my own home, my own life.

You can go to bed any time you want here, do anything you want to do. On a typical day, I’ll go to the bank, go to the McMaster Centre. I go to the bingo with Jimmy. I do my shopping, usually at Farm Foods and Somerfields - I get my tons of fags! I do try to keep fit - even though I smoke - I do swimming and go to the physio. If there’s a match on at the weekend, a pal, Sandy, sometimes comes round to watch. You’ll have guessed I’m a Celtic supporter - that’s why the living room’s painted green. I didn’t do any of that before.

Lesley and Damian write on the whiteboard in the kitchen what’s happening so I can remind myself. We discuss when they’re going to support me because it can change depending on what I want to do or need. I’ve got hospital appointments but the days and the times aren’t always the same, or at Christmas I might want support to go to a party at night. Blythswood and Red Cross were like being back at school. Dinner at set times, your room at set times, even going for a smoke.

I collapsed one day in my flat when I was about twenty and they found me lying on the floor. They took me to the RAH [Royal Alexandra Hospital]. I met Alan when I was in the RAH. We were both in there, and he became a great friend but I don't know where he is now. Vivienne in the post office might know where he is... Lesley and Damian are going to help me to meet him again.

I moved into Blythswood because it had the space for the wheelchair. When it closed, I had to go to Red Cross for two years. I'd been planning to get my own house. I'd never been to Irvine, didn't know anyone else who lived there. It was boring. I just had a room. They told me when to get up, gave me a shave, told me to go and have breakfast and then back to my room. That was it.

I don't want to talk about this anymore. It was miserable, I was miserable there, why would I want to talk about such a miserable time?

'The Man behind the Mask', that's how I want people who support me to see me. I find that people treat you as if you're knackered, because you're in a wheelchair. That angers me, that assumption. Trust and honesty - that's what you need in any relationship - and being able to control who supports me or not. I know what my support workers are doing and if I need support with something then I'll ask. I can be a bit sarcastic so it can help if my friends and support workers have a thick skin! But I don't mean to offend anyone, I just like a good laugh and only do it with people I know really well and they know me.

I've got friends at the DRC [Disability Resource Centre] now, done a ceramics class and confidence building classes. I've learned a lot about local history going to the history group - that was where I met Marion. I'll tell you more about that in a minute. Another great thing was my 40th birthday. That was just before I met Marion. I had a huge party at The Knights of St Columba - great food, great music, great company.

Trust and honesty
- that's what
you need in any
relationship -
and being able
to control who
supports me or not.

We lived in Paisley, Ferguslie Park - there was me, my sister and five brothers. I always had balance problems, used to get arrested when I was at school because people thought I was drunk. I got sent away when I was maybe about 8 or 9. The others all went to a different home. When I was about 13, I went to - I'll just whisper it - near Stirling. I'm not going to talk about that. I don't talk about that. I was allowed back home to my mother every second weekend but I wasn't allowed to go on the same weekend as the others. I remember going on the train myself. I left when I was maybe about 16, back to live with my mother.

Got my own flat when I was 18. I can tell you exactly when I got the keys: the day before my 18th birthday. I was desperate to get away - I couldn't get in there quick enough. I don't want to talk about why. The social work got me the flat off the Council because I was a special case but then the only flat the b*** offered me was two floors up! I had a different wheelchair then, not this big electric one, but not one that folded up either. So I just had to bump myself up and down the stairs on my bottom and drag the wheelchair up or down behind me.

I think I had about 3 different flats off the Council - one was above a fish and chip shop. I liked having my own place, doing what I wanted but I didn't know how to do things, what you were supposed to do. I never got support. That and two floors up - I wonder if that's the reason I got ill.

My house is great. It's mine - I'm the King of the Castle. I did my house myself - chose the colours, helped with the painting, did my garden up. The support staff helped me to think about things - we got a unit for the TV and the DVDs so I can reach them myself, changed carpets for laminate floors which is better for getting around.

This house is for someone in a wheelchair so I'm able to do more for myself, even the housework. The kitchen units are lowered so I can do my own cooking. Even the wardrobes have low hangers. Marion has a wheelchair too and it's fine for both of us.



We get married
on the 3rd March.
I never thought I'd
see that day.

Marion's my fiancée. I met her at the history group. She must have liked me because she asked Lesley if she thought I'd go on a date with her. I was a bit worried about it - it was a very long time since I'd done that - so I asked Marion to come for dinner at my house, and I asked Donna if she would stay to support me. She did for the first time, but then we kicked her out!

I went down on one knee...no I didn't! We got engaged on Valentine's Day last year. I wasn't really thinking further than that, not about getting married. But then Neil was down one day and he said "so when are you getting married then?" He really recommended it. On banking days I like to go to The Coffee Bean - so that was the scene of us deciding to get married.

At Blythswood you had money, but not enough. You didn't have your own bank account. Now I've got three accounts - my personal account, a joint account with Marion for the house, and a savings account - mostly for the wedding just now, but before it was for saving up for things like more DVDs and CDs. I've got plans for the house - or I should say mine and Marion's house. Things will change in the next year, I'll have married Marion, and been on a plane - I may need a parachute! I've never been on a plane - but we'll get on one to go on a honeymoon.

We get married on the 3rd March. I never thought I'd see that day.

I'm settled, more relaxed. I would say that life now is fantastic. I wouldn't go back. I couldn't go back. My, our, favourite song is by Aerosmith - I reckon it's my attitude to life now.

"And I don't wanna miss a thing
Don't wanna close my eyes
I don't wanna fall asleep yeah
And I don't wanna miss a thing."



I've got a good life now, which I enjoy...I am happier now because I'm more independent. Before I came here I'd never been on my own, never.

LAURA

“Sometimes you need time just to be on your own”

Over Laura's first year in her own home, her support workers gradually helped her to find her new world - from having the confidence first to open the door, then to step over the threshold, to move down the front path, to the end of the street and eventually to go into the town centre.

I was at Eastpark House from when I was 14 until I was 22. They were bad to me there, they also did everything for me which took away my independence.

I've got a good life now, which I enjoy...I am happier now because I'm more independent. Before I came here I'd never been on my own, never. Having my own house means I can decide when I want to be completely on my own and when I want company. Sometimes you need time just to be on your own. I'm on my own every morning between 8.00 and 10.30 and later on if I want. I really enjoy time on my own.

Karen, Tracey and Lesley are my team. They have all been with me since I moved 5 years ago. They support me to do things I like - shopping in Braehead and Glasgow and clubbing in Paisley and Glasgow.

I want to go to college to do a health and beauty course, and I'm thinking about a cookery course too.

I get a lot of visitors - I like it when my friend Vince visits me and I make him lunch. My family visit me lots too. I save my dirty dishes if I know my Dad is coming! I go trips and holidays too. I've been to Blackpool twice and I like Blackpool Tower. I've been to Dublin and I'm going to London this year. I went on a family holiday to Barcross. I stayed in a lovely lodge. I even tried trampolining! Remember that trip to see my granny? She lives in Kirkcudbright so it's quite a long way and the roads are terrible - all bends and narrow. Karen was driving my car, saying she hated the road and she was really worried, I kept telling her it would be fine, I said "you're doing OK". That was so funny - I was supporting her that day.

When I first moved it was really scary and I found the thought of going out very stressful, it took me a long time to gain confidence. I am happy to go out and about now and enjoy trying new things and going to new places.

Laura's Mum, Jean

We had been looking around for a group home for Laura - that's what we thought would be best. In November we met Margaret and by June, Laura had her own house. It was quite scary - we had never expected that for Laura, hadn't thought it was possible. Seeing how happy Laura is now, we couldn't have been more wrong.

JIM “I’m doing it myself here”

Jim is 56 years old and spent 41 years living in hospitals. There was strong resistance from health professionals to the plans for his move into his own home. His prospective support providers were told “he’ll need a suit of armour for his epilepsy, 24 hour one to one care, 7 day sleepover support.” He asked Lorna, one of his support workers to sit with him as he told his story.

When I was wee, I lived with my Mum and my Dad and my brother. My brother works on the buses - I see him sometimes on his bus in the town. I was 15 when I went to Lennox Castle. It was after an old firm game - I was going home and was at the bottom of the flats. The guy was drunk and attacked me and I lost my eye. My father called the police and the guy was arrested and got the jail. He went to Barlinnie: I went to Lennox. I wouldn’t go to Old Firm games now, don’t like to get into situations where things could turn.

At Lennox it was all right, except that a big fat staff nurse gave me a hard slap on the face. My father phoned the police and he got the sack - but I found it hard to settle down after that. Then I got moved to Merchiston. I was in quite a few of the cottages. I don’t know why they were called cottages - there could be a lot of people in them - it’s just what they were called. It was all right, but staff hurt people. They hurt me, so I used the nut [head butted them] and got sent to the misconduct cottage. We were locked in there. I didn’t do things for myself - the staff gave you a shave, they took your teeth, they took your eye at night and put it in a safe.

When I came here, there were five staff - Derek, Jim, Lorraine, Lorna and Ian. I used to ask Ian if I could go out - I didn't know I could go out by myself. Staff used to sleep with me. I had someone with me all the time, but no now. It's just Lorna and Peter now. Lorna knew me when I left the hospital but then she left - I asked Margaret if Lorna could come back and she said yes. I picked my own team.

I'm friendly with Peter although I fell out with him once. If we fall out we say sorry to each other, have a wee hug and I settle down - we go on as normal.

I like people who show me what to do - who teach me things. Here I have a shower, a wash and a shave; I do the sweeping and the hoovering. They've shown me how, taught me and now I'm doing it myself.

I've got my routines. In the morning I get up myself and I go for a roll and egg, get the paper and cigarettes at the shop and then come back. I do the crosswords - enter the competitions. Sometimes I get messages for the neighbours - Maureen upstairs and Cathy next door. I get their paper for them - I'm quicker to go down the shop. During the day I'll go to the job centre. I used to work in the carpet shop, but the work was too heavy so the man told me to leave. I've applied for a few things - phoned up myself. After dinner I like to be on my own, I watch the game on TV, watch a film, do my crossword, make a cup of tea. Sometimes I go to bed at one in the morning.

I got burgled one summer. I used to leave the living room windows open at night to get rid of the smoke. One night after I'd gone to bed someone broke in. They took my wallet, my [allowance] books, my watch. I used the emergency button [call phone] and the police came, calmed me down. Now I need to close all the windows at night and if I go out, shut the blinds and don't leave cash lying around. That's what I've learned.

I don't even worry if the staff aren't there - at first I did. Now I go places myself, but I don't like going out myself at night. I get a taxi to my Dad's and go on the bus myself during the

Sometimes I get messages for the neighbours - Maureen upstairs and Cathy next door. I get their paper for them - I'm quicker to go down the shop.



Lorna knew me when I left the hospital but then she left - I asked Margaret if Lorna could come back and she said yes. I picked my own team.

day. I go to the hairdresser's myself, the dentist, the health centre... I've got false teeth - clean them myself. When I came here the staff had everything to do with my eye. Now I take it out myself at night and I put it in the pot to be sterilised. I can manage alright myself here.

I've got epilepsy - they didn't want to let me out because they said it wasn't safe. When I came out the staff had to give me the tablets about six times a day to stop the seizures. Even when I stopped having staff at night, they still gave me my tablets during the day. Now I just get a box in from the chemist. Here I hardly ever have any seizures, don't need to take diazepam any more, only take one lot of the tablets now. I've even been swimming. I'd never been in water like that before. I had a lesson and we ended up under the water because I had a seizure, but we coped. No sure I want to go again though.

I've learned I can do things. I've got my own bank account, my own card. I don't like going to the machine [ATM] on my own, but when the bills come in it's me that opens them and then Lorna or Peter comes with me to the bank to get the money and then I go to the post office myself to pay them. I take my treatment before I go. Sometimes I buy a roll and sausage at Trento's on the way.

Lorna or Peter come to the football with me but next season they're going to support me to go to a game on my own. Maybe at first they'll come with me and wait outside. I go up to the pits [at Merchiston Hospital] to play the five aside. I meet my friends there. That's my cup on the television - I took the cup at the competition in Geneva. Won the cup. When I got back Mum and Dad were waiting for me off the plane, hugging me and kissing me and everything. Mum died last year - that was a hard time. It helped having Lorna to talk to.

I want to do more things on my own. That's my hope. Lorna and Peter are helping me bit by bit. I wouldn't go back to the hospital - life is getting better and better here. Life is more peaceful here. Here I can help myself.

Here I hardly ever have any seizures, don't need to take diazepam any more, only take one lot of the tablets now.

IAN “I go out every day”

Ian has a life-story book and, using this, he and his support workers talked about his life.

I was an only child and lived at home with Mum and Dad until I was 40. Then I moved to Westlands. I lived there with about 40 other people for 18 years until I moved here. I was happy enough at Westlands, but I wanted more. I was the DJ there and had lots of friends, but I didn't get out and I only got pocket money. The thing I love now is that I go out in the car every day - I revel in that freedom. I've got the only team where everyone can drive - that's an essential. The other thing I look for when I'm interviewing for staff is that they're happy. I don't have much strength in my arms, and I have someone with me all the time.

The thing I love now is that I go out in the car every day - I revel in that freedom.

I've got the chance now to do more and to try new things, like with Andrea who lives on a farm so she took me out there and I fed the horses. I've got a season ticket for St. Mirren - that's the team to support. I got to choose what colours to paint the house and I went out to pick my own furniture. I hadn't done that before.

I spend the day going to visit neighbours, or I go to the park, I like to feed the swans and signets, go into town, go to the KeyStore and sometimes Braehead. If I'm home I listen to music. No one here passes without saying hello. Sometimes we all wash our cars together at Ian's house. He's a bus driver and he's got a hose. It was a good laugh when we had a water fight. Wee Conner likes to visit me - it lights me up when he comes. I don't see him so much in the winter - he doesn't play out as much.

My art is important to me. I go to classes twice a week at Reid Kerr College. The staff helped me to get some of

it framed so I can have it on the walls in my living room. I need to get up at a reasonable time on art class days, but the other days I do like a long lie. I could never have that at Westlands - had to be up at 7 every morning. I think now I'm 61, I can have some long lies. When I'm sleeping in, the staff can get on with the housework - I can't help with that anyway, so when I'm up I prefer them to be supporting me with things I can do and enjoy.

I've been on a big trip - we went to Jersey for a holiday, for 7 days. It wasn't just the holiday I liked. I loved all the stuff we needed to do before - we had to decide where to go, and how to go. Then we made bookings. We had to think what to take and do the packing.

The day I got my own car is my best memory of being here. But just being here, in my own home, makes me happy.

I think now I'm 61, I can have some long lies.



I have two things I look for when I'm interviewing for staff - that they're able to drive and that they're happy.



The first time I saw
Connie I knew she
was the one for me.

NEIL AND CONNIE “Our own front door”

Neil and Connie are married. The Thistle Foundation supports them individually and as a couple. They told their stories individually.

Neil

I was born on the 27th of March 1970 in Robroyston Hospital. My mum put me up for adoption as she felt there would be no support for her. When I left hospital I went to Park Lodge children's home, I remember being bullied by the other children there and at school. If I had an accident I was either smacked or left to sit in it for hours by the staff. Later I was moved to Eastpark children's home in Glasgow. I remember happy, good times and bad times there. We lived and went to school in the same grounds. Eastpark was run like a hospital, the staff wore nurse's uniforms and they kept their distance. We weren't encouraged to have friendships with other children, and certainly not with staff.

In 1989 when I was 19 I left and went to Motherwell College as a residential student, I stayed in Stuart Halls and did an independent living course. I'm going to skip through the next bits. In 1991 I went to Red Cross House in Largs - boring. Then in 1992, another Red Cross House in Irvine. I had a bit more control there over what I did, but I spent another 2 years doing independent living courses. It was here that an old social worker helped me to make contact with my mum and we see her regularly now.

Then in 1994 I moved to Blythwood House, I liked the homely atmosphere and the freedom to get out and about.

It was very relaxed and the staff were really good. When it closed in 1998 I then moved to The Thistle Foundation in Edinburgh to what I suppose was a residential group home - it was there that I met Connie, my future wife.

Connie

I was born in Pathhead and lived with mum and dad, 3 sisters and my brother. I liked spending time with my sisters when we were younger but, as we got older, two of my sisters moved away although I continued to spend time with my brother and other sister. When I lived at home I was told what I was to do. I didn't like being told what to do. When my mum died, I moved into Wighton House, a residential home in Edinburgh. This is where I met Neil, my husband. He left Wighton House in 2001, he got his own home in Renfrew, near his Mum and Dad. I moved to Dalkeith and into another residential home. However, Neil and I continued our relationship travelling up and down the M8 and in October 2002, I moved to Renfrew to live with him. We got married in May 2003.

Neil

The first time I saw Connie I knew she was the one for me. We struck up a friendship very quickly. Originally I wanted to stay in Edinburgh, but when I heard that at High Mair I could have my own house and own space, I changed my mind and when the time came for me to move to my new house I knew that I wanted to ask Connie to marry me. Connie was eating dinner at the time I decided to ask her, she didn't respond for what seemed like ages. I began to think she was going to say no but I was delighted when she finally said yes.

We had 40 guests celebrate with us during the day and a further 80 at the evening reception. I didn't think my dream of a wedding would come true 'till I met Connie... I went from loneliness to a wedding ring. We're a couple, doing what couples do - enjoying being together, us and Tessa [our rescue dog]. We've got friends, family. When we went on holiday, Mum and Dad 'dog sat' for us.

There is nothing that I would change about where and how I live now. We have great neighbours, my own life, and I'm in control of making my own decisions (when Connie lets me!).

Connie

It's great now living in my own house. I don't have people telling me what I can do. I make my own decisions now. It was difficult though because when I moved my sisters weren't happy, but it was my decision and this cost me my relationship with them. It was a price I was willing to pay to be with Neil and have my own house. Three years on, I am starting to build relationships with two of my sisters and that's brilliant!

I knew that I wanted to ask Connie to marry me. Connie was eating dinner at the time I decided to ask her, she didn't respond for what seemed like ages. I began to think she was going to say no but I was delighted when she finally said yes.

I have made a lot of new friends since moving to Renfrew and very importantly to me, I have managed to get a job that I love doing. I work voluntary on a Tuesday afternoon at Capability Scotland as the receptionist. The idea for my job came from doing an Essential Lifestyle Plan. After applying for many posts I was successful at Capability. I have good working relationships with my colleagues especially on the works night out!

I feel that my life is much fuller - at times there is not enough hours in the day. I feel much more confident as a person and my friends can see this too. I really take a lot of pride in having my own home. I love keeping it looking nice and buying things to keep it looking good. One of my goals is to show off my house to my sisters - this would make me feel proud and happy and maybe one day I'll achieve this.

Neil

I was involved in interviewing for our staff team. We've got Veronica, Alan and Carole. We have support there when we want it, not when they do. We can do anything without question. We're able to be spontaneous. Before living here I got pocket money and had no control over who was providing my support.

My life now is rich. I can give you a list: being married, owning a dog, spending my own money on what I want, going out, eating when I want, eating what I want...just deciding what I want to do and when, living in my own house. My own front door...I can't put into words how good it is. I thought it was an impossible dream until Thistle made it a reality. Things have happened for me, really important things, that

I don't think would have happened if I had been supported in a different way. My faith is very important and I was baptised 2 years ago. I'm very involved in my local church and the minister is one of my friends. I'm concerned about community issues - drinking, drugs, anti social behaviour. I'm a member of the SNP. My ambition is to be Prime Minister - to make a hell of a difference.

When I think about how life was...I used to think: "why am I living? I shouldn't be here. I shouldn't have been born". Now I see myself as a very important person in society and know that I have a life that is worth living. I tell my story to other people. I want to help people who are in the same situation as I was in just a few years ago, to inspire them that you can have your own life, you deserve your own life. I couldn't bear to think of being supported in any other way - don't make me go there.

Now I see myself as a very important person in society and know that I have a life that is worth living.

BARRY “Dinner time, first sitting, second sitting, third sitting, sit down”

Barry’s story is also his family’s story and was told on his behalf by his mother Ann, and one of his support workers.

Barry had been labelled as having ‘very challenging behaviour’. As a condition of his release from hospital, his house had to have carpeted walls, high level TV, special plastic furniture, and he had to have a padded helmet. He doesn’t have any of that now. He didn’t have any of it before he went into Merchiston either.

Barry was a great we’an. We just had to watch for fits - two a day. It was really terrible to watch. I split up from his Dad and it was after that they told me Barry had epilepsy, and the doctors said “he’s always going to be a baby.” I treated him just the same as the other four. He had the freedom of the house. He used to go to his brothers’ rooms when they had pals in and listen to their music. That’s why he likes all that Heavy Metal stuff - he grew up with it. When he came home from [Clippens special] school, the wheelchair was folded away, in the cupboard. Barry moves around on his bottom. He uses his hands and feet to propel himself. He was always banging doors so we just took them off when the Council said they wouldn’t repair them any more.

We had to fight for everything - a ramp, a shower. I got a bit of a shock when Barry's body started to change and I was desperate for a changing room. I asked for the room next to the toilet to be converted, because if the other kids had their pals in I had to tell them to leave the living room, so I could change him. I didn't think that was right - he deserved to have some privacy.

I think Barry was confused about what was happening to his body and he was probably going through all that usual teenage hormone stuff, but I started getting reports that he was being violent to the staff at the school. I don't think any of it was intentional. How else could he tell us he was upset? It turned out that, while the plans for the house were being discussed with us, behind our back they were planning to move Barry to Merchiston. It wasn't my idea or my decision: I thought he was to be at Clippens until he was 18, but he was moved at 17. The school and doctors said I wasn't coping.

We were told we couldn't see him for a month: it devastated everyone in the house. When we did go to see Barry he wasn't like my son or a brother any more, he was like a zombie. When we asked why he was like that, the staff said they'd given him medication to keep him calm. Barry had never been on any medication apart from what he had to control his epilepsy. He wasn't dressed in his own clothes, and he just sat - Barry, who was always so active.

We weren't encouraged to visit. When we did go, we got told to stay in the waiting room, or that it wasn't convenient, or Barry wasn't ready. When we eventually got in there was never any privacy. It was shared mixed wards and the staff were in a kind of viewing room with glass windows and locked doors, so if something did happen it took them a while to get there. I felt uncomfortable. You never knew with the mix of patients if something was going to happen. We even had to ask for a cup of tea.

Barry would be chapping on the window as we left. It just broke my heart.

When we did go to see Barry he wasn't like my son or a brother any more, he was like a zombie. When we asked why he was like that, the staff said they'd given him medication to keep him calm.

We stopped going and started getting him home for weekends. I had to call on the Monday, to make the arrangements for his brothers to go and collect him on the Friday. On the Sunday night there would be calls from Merchiston asking where he was, saying we “hadn’t returned him on time”, like he was a library book. When Barry came home, friends came to visit - they would just drop in and I wasn’t going to say they couldn’t because Barry had to be back.

Barry didn’t live while he was in there; he just existed.

I knew there were plans to close Merchiston, but what was I supposed to think? Barry hadn’t even gone on the hospital days out because they said he was too violent. So when I got a letter from The Thistle Foundation I thought they were another institution. “Who are these people? What if something happens and he can’t tell me? I can’t do this all again”, I thought.

He’s 30 - it’s right that I’m his Mum and I come to visit him in his own home the same way I visit his sisters and brothers.

I was nervous and suspicious but I started to trust the people that were going to be involved in supporting Barry. When I saw where he would be living, I felt as though someone had lifted a building off my shoulders. He has his freedom back, he’s back to the person we knew. He has a normal life and he’s entitled to that. His carers are great. I used to say Barry would always be with me, but I know he has better support and a better life now than I could give him. He’s 30 - it’s right that I’m his Mum and I come to visit him in his own home the same way I visit his sisters and brothers.

Lots of people know Barry and he enjoys being part of a group, included in conversation. Barry likes creating noise and movement. He still repeats an ingrained hospital refrain: “dinner time, first sitting, second sitting, third sitting, sit down Joyce”. He is now supported by people who know him well and who listen to what he is communicating - a network which includes paid staff and family members. He has his own space and one-to-one attention. His house is ordinary, cosy - a leather suite, TV in one corner, a stunning Christmas tree in the other.

A typical day for Barry is getting up and having breakfast - he loves his food; he might go for a run in the car to the coast, have a pub lunch or go round to visit someone. Sometimes he has a class or goes swimming. At night he'll listen to music or watch television.

He sees a lot of his sister Traceyann and his mother Ann, and they telephone often too. Barry did not see them as often before because the family so disliked the hospital. Since moving to his own home, with his own support, his family say that they have been able to take their natural place again. Barry recently went on a family holiday and instead of being supported by his paid staff team, he was supported by his family - Mum, sister Traceyann and Steven, Traceyann's husband.

Barry's nieces and nephews love coming to visit their Uncle Barry. Ann did not want them to see how Barry was living in the hospital, so until he moved to his own house with support, he was just a photo on the wall.

Barry was 30 last month and had a big party with lots of people. He was encouraged to mingle, but he saw his place mostly sitting with his brothers and their pals - just smiling at them, being one of them.



Barry's nieces
and nephews love
coming to visit
their Uncle Barry.



I've got my own front door and I can see straight out to it from this seat in the living room. There's a camera so when the bell rings I can see who's at the door and I can open it at the touch of a button. Just as well, because I get a lot of visitors now.

TOMMY “Just getting out to look at the world”

Tommy is a man who uses few words to speak, but who is easy to understand once you get to know him. He is patient with new people while they are doing this. Tommy’s support workers helped Tommy to communicate with photographs and videos about his lifestyle, who he is and what is meaningful to him. Rena, Tommy’s sister, added to the story.

Tommy was born in December 1930, one of 5 children who lived in Espedair Street in Paisley. He lived at home until he was 5 years old, when, on 21 March 1936, his father took him to Broadfield Hospital in Port Glasgow and asked them to take over guardianship of Tommy. No-one seems to know why.

Rena recalls getting the bus with her mother to visit Tommy at ‘the castle’ every weekend. He lived in this hospital for 40 years. He had no formal schooling. Then, in March 1976, he moved to Merchiston Hospital. The first correspondence between the hospital and his family was in 1980. In 1999, the Merchiston Advocacy Project started to work with Tommy, supporting him to claim an ordinary life. He moved to his own home in High Mair in Renfrew in early 2001, aged 71.

After 65 years in long stay hospitals, Tommy is not interested in remembering this. He shows some photographs from his later years at Merchiston. He is standing next to smiling ladies, probably staff, on a hospital corridor. He can’t

remember who they were. Now he's happy to be talking about life after the hospitals.

I've got my own front door and I can see straight out to it from this seat in the living room. There's a camera so when the bell rings I can see who's at the door and I can open it at the touch of a button. Just as well, because I get a lot of visitors now.

That's Bill, he's a comedian, always telling jokes...knew him from Merchiston. He lives in Paisley now, I go to visit him, he comes to visit me. That's James and Frank. We like to meet up for tea and cakes. I never say no to a cup of tea. I go and visit them too. I've got a lot of friends - when I could walk better I used to go round the cottages at Merchiston getting cups of tea with them. Most of them have moved to different places now, but not too far. Jean only lives round the corner. That's me at Gloria's house one day with James, what a laugh - she couldn't believe John had just eaten the chocolates she'd brought as a present for Frank! I couldn't stop laughing - I'm still laughing about that yet, every time I see that clip. Her house is all pink - that's what she wanted when she got her own house.

A lot of my friends from Merchiston go to the ENABLE group so we have tea and singing and dancing. I like a good party. That's me at the Jumbulance Ball in Bellshill - it was a ceilidh, I got a lot of dances, Martin didn't get one! I've made new friends through Jumbulance.

Brendan [Martin's son] is a great accordion player. Sometimes I go to his house and he plays for me. That's my favourite music - Scottish and Irish. I'm always playing CDs. Listen, that's me playing my keyboard. I keep it behind the sideboard back there. I've been to a fair few concerts as well - went to the Edinburgh Tattoo last year.

I go on a Wednesday to the SPRED group at St Peter's. I used to go to Mass in the hospital but now I go to the ordinary 12 o'clock mass at St James. I'm in the choir too. We're called 'Amen Corner'. I've got choir practice every Monday evening. I've got a lot on.

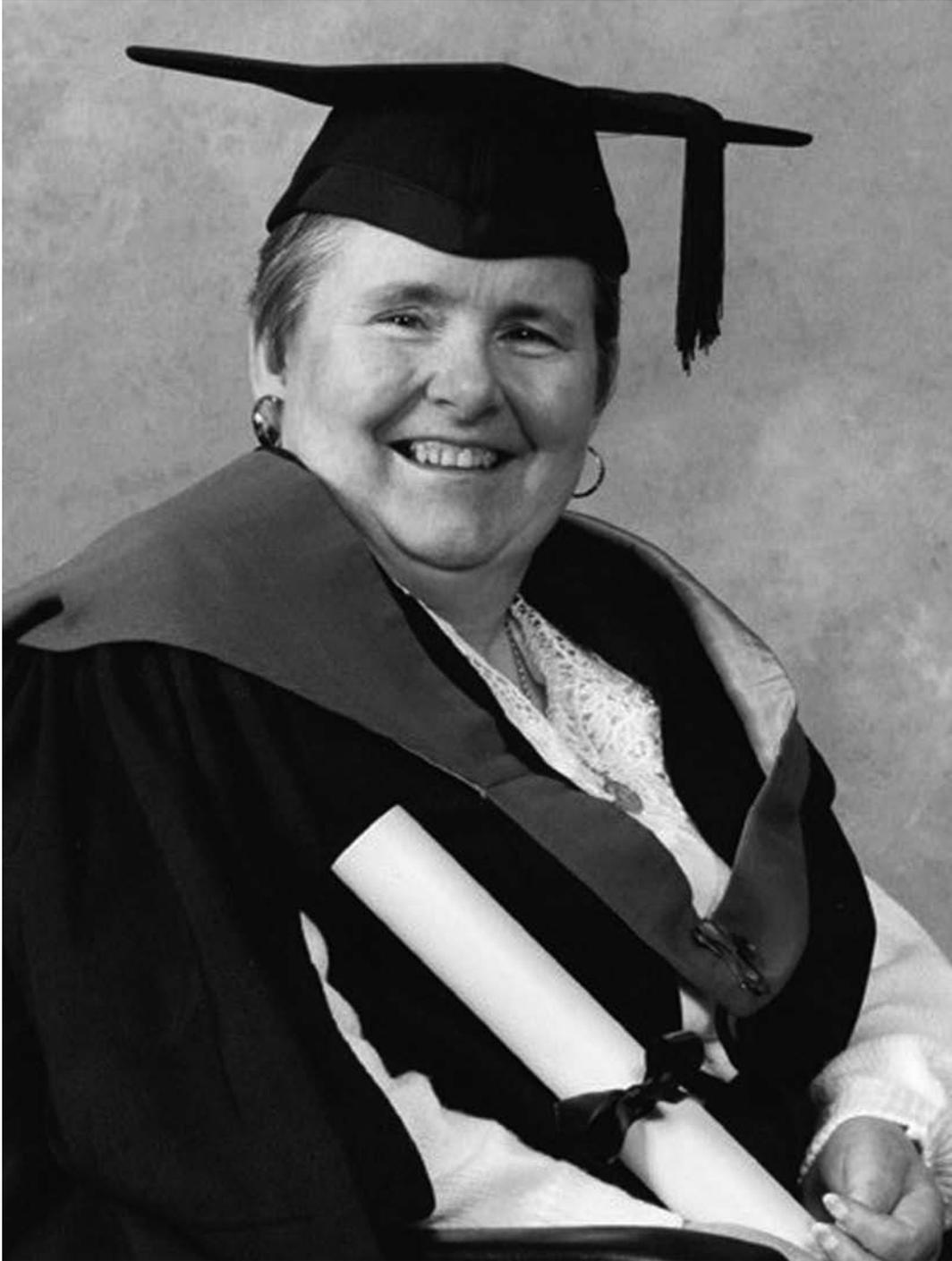
Going on a picnic in the car. Just getting out to look at the world - driving in the country, listening to music and singing along in the car. I can't get enough of it.

I went on my first holiday when I moved here. Now I've been to Lourdes three times and Knock twice. It's part pilgrimage, part holiday. The last time I went with Jumbulance. It's a huge big bus with everything you need for wheelchairs, even beds. Martin went with me. It was a long journey, but I didn't mind. When we got there...a proper hotel, ensuite bathroom, Karaoke in the bar...they called us the VIPs. I was the one from our group that took the banner. I was at the head of the procession. At Lourdes I went in to the baths - the full immersion. Some people don't like that but I wanted to try it.

I've got pages of photographs of this - my car. I picked it. It's the best part of my life. If I could spend all day in my car maybe I would. We went to Braehead this morning to do a bit of Christmas shopping. Nothing for myself today, but that's where I go to get new clothes. I like to look smart. Going on a picnic in the car. Just getting out to look at the world - driving in the country, listening to music and singing along in the car. I can't get enough of it.

That's me having my lunch. I like my food. Here you choose what to eat. Morag asks me what I want. We might get something out the freezer. We might have a bite out - steak pie at the Abbotsinch, that's good. I have my meals sitting at that table, so I can look out the window. I love living here, looking out the window there's always something to see. I don't want to miss anything. I know everyone here, and they know me. When it's warmer I sit at the front door, watch the world go by, the children playing. They'll say hello or come in for a visit. I went to Simon's 50th birthday party, he lives up the road.

Are you having a cup of tea now?



I'm quite a private person, so I also like a lot of time on my own. In my own home, with my own staff, it's easier to be relaxed.

LORRAINE “Every day now is about making choices, about every little thing”

In 1998, with Barry Robertson from the Johnstone Writers' Club, Lorraine wrote 'Survive', the story of her life up until then. As she found it difficult to talk at length, she agreed that information in that booklet could be added to her more recent story.

I was born in 1942. I went to Notre Dame Convent Girl's School in Glasgow.

In my last year, from time to time I had double vision and lost my balance. It was the early signs of MS but I didn't know it then. I had to leave my first part time job, and later that year I had to leave school too.

Later on, I lived in Clarkston with my mother but by the 1980s my condition was getting worse and the district nurse was calling three times a day. My mother was also deteriorating, slowly becoming almost blind. Although we had a home help, we weren't coping, and I decided I should leave and go into a private nursing home. It was 1984 and I was 42; most of the residents were elderly and had dementia. Words can't describe how distressing it was. I moved to another nursing home, which was much quieter and better. My mother died two years later.

My physical immobility was increasing so I was desperate to do something with my mind. I started an Open University degree course, studying with audio tapes and the TV and relying on my good memory and special friends, like Jim McCormack who gave me the motivation to continue. I got my Degree in 1994, the same year I went to live at Blythswood House in Renfrew. It had all sorts of equipment for disabled people. It was warm and the carers tried to make life bearable. Blythswood closed in 1998 and I had to move to Red Cross in Irvine. I didn't see as many people there, and didn't go out. Margaret McMahan stayed in touch and in 2000 I got the chance to have my own home here with a personal staff team.

I wouldn't want to say anything bad about Blythswood and Red Cross. The staff did their best but I didn't have the freedom I have here. You didn't get individual attention. You couldn't choose how to lead your life. I can't move much - just my head and neck - and I get breathless and tired. Here I make my own decisions about when I want to rest and my support team listen to that. I have a team of 3 personal assistants - Nan, Helen and Caroline.

I'm quite a private person, so I also like a lot of time on my own. In my own home, with my own staff, it's easier to be relaxed. I have help in the morning till after lunch and then I like the time in the afternoon to myself. One of my PAs [personal assistant] is here in the evening. The times are to suit me. I choose to be on my own overnight, but I have access to 24 hour support - that's vital. [Lorraine can use her head to move beads around her neck to trigger a telephone-based alarm which then links to a 24 hour staffed centre]. I couldn't imagine having someone here 24 hours a day - I really wouldn't want that.

I used to fear change. Now I know that if I hadn't come here I wouldn't have been able to do and see the many things I have. With my own car and a volunteer driver, my own staff, I'm free. I'm interested in history and have been on holiday to the Borders, to see the Abbeys in Melrose and Jedburgh. I like going to the garden centre at Cardwell. I go to mass every Sunday at the local church. I've had this picture of

I go and see my friends. They come and see me at home. I have friends from all over.

Salvador Dali's 'the Crucifixion' [Christ of St John of the Cross] for a long time, wherever I've lived, but I'd never seen the original. Now I've been to Kelvingrove Art Gallery to see it. I think it is a very strong painting.

There are a lot of people in my life - they like being with me: Jimmy, whom I've already mentioned, is in Eaglesham - he helps with typing what I say; Maureen, who is a wonderful help; Bill McGuire, another friend who visits and reads to me; Father McLean, who was in Largs but he's gone to Dounreay now. You could say that Father McLean has followed me about...but not in a bad way! I go and see my friends. They come and see me at home. I have friends from all over.

When I say I get individual attention, I mean that in its fullest sense - the staff absorb who you are and what you need, to attend to your requirements. I need certain foods and I like to have a healthy diet - I'm the healthiest eater in this development! I like to keep track of the time in the day, so I always have a clock facing me - they understand why it's important for me.

I'm a born academic, but in the homes there wasn't the facility to have your own bank account. With having my own house, I'm able to manage my own money and I have help with that. I see it as a complementary relationship. I can make choices and decisions and Nan, Helen and Caroline support me with carrying these out. Having Nan by my side is very important. This is the longest time I've had the same staff. We have our ups and downs but we know how we work together.

Every day now is about making choices, in every little thing; what to eat, how to spend my money, where to go, when to go. If it's good weather I usually go to Tesco to do the shopping, but if it's really bad weather we use the internet. There are highlights, like choosing to go down a zip slide - people say I'm not afraid of anything.

In 2006 I plan to decorate the house. I'll learn a language - Italian - from tapes. I'll visit Ireland to see Sister Mary, a very old friend of mine, who took a stroke this year. I need a

lot of support to arrange a trip a like that. Perhaps the other big difference from life in the homes is that I can make real plans and know that I will have support to fulfil them. There are physical constraints to be overcome but I can make the decisions about what I want to do and then I depend on dedicated support from people who know me and can work with me to make it happen in the way I want.

Perhaps the other big difference from life in the homes is that I can make real plans and know that I will have support to fulfil them.

ALISTAIR “No going back”

Alistair does not use words to communicate. His story is also a family story and was told by his mother, Mary, supplemented by DVDs, made by one of his support workers, which Alistair enjoys watching and sharing.

Alistair went to Stanmore School when he was 8. For all but his last year, he slept in a bedroom with 4 others, just along the corridor from his classroom, so he didn't even get fresh air going out to get from one place to another. He used to come home for the school holidays but as he got older I couldn't lift him, so we had to make other arrangements. You couldn't always get 6 weeks in one place. One summer, a taxi brought Alistair from Stanmore to Kilbarchan and I had to take him to East Park and back to Kilbarchan. It felt like he was a parcel; like I was dumping him. It was so disruptive.

Giving him this wonderful package felt like a miracle.

At 14 we started worrying about where he would go when he left school. We thought it would be a residential home but the options were either miles from home or with no facilities. We looked at lots but nothing was right for Alistair, for a young person. We spent 4 years worrying.

We'd never heard of The Thistle Foundation until the social worker told us about this opportunity. There was a meeting and then the school took Alistair and me to see the house. We got a budget for furniture, and everyone in the family helped with choosing the furniture. Diane, Alistair's eldest sister enjoyed helping with this and there were housewarming presents as well. He moved in on 19 September 2001.

Giving him this wonderful package felt like a miracle. Our house was adapted for Alistair but nothing like the house here. It makes the support so much easier - the right space for the wheelchair, the adjustamatic bed, the tracking hoist. Life with me at home with carers would have been terrible. He had it once. There was a half hour slot in the morning where the carer came in, and then he was in his pyjamas by 8pm because that was when the carer could come. If he'd had a bad night and we'd both been up, we couldn't just decide to lie in. I still had to be up again and dressed, exhausted, for the carer to come in the morning at the usual time to wash and dress Alistair. Now, if Alistair has had a bad night, the staff change their hours. The team work on a rota so are able to cope with Alistair not sleeping.

Alistair went to school locally in his early childhood and his family home is only a few miles away in Linwood so he has friends and neighbours who know him. Most days he is out and about. People say hello to him in the street. He gets support with all the day-to-day things like the housework, paying the bills, going to the Post Office and the supermarket. Tesco is not his favourite place, but he likes going shopping to the Keystore.

He has quite an organised week: music class at college on Mondays, where everybody knows him and the music he likes; sessions at the Anchor Centre; and the sensory room and hydropool at Merchiston Hospital, which he really enjoys. He goes to the ENABLE club, and there are always parties, dinners and discos. At the weekend he might go along to a football match, have a curry dinner and a lie in on Sunday.

The staff help Alistair to choose what clothes to wear and he likes going shopping for new clothes. He likes to look good. He also loves having a bubble bath and a shower, which he can have everyday now. At school, he was just one of the crowd. It wasn't that staff weren't caring, but they didn't notice the small things and they do matter. You'd find him wearing a tracksuit top and bottom that didn't match or his hair not washed and combed.

He tries a lot of things. It's a time of your life where you don't know everything about yourself yet. He's trying life out.



They saw Alistair as someone in a wheelchair. Now he's just the chap who lives next door.

There are five people in his staff team and they each bring something different to Alistair's life and he brings something different to each of theirs. Most of them have been with Alistair for a number of years now and that consistency and individual care makes a difference. Alistair has matured and been allowed to mature because the staff attend to details. He tries a lot of things. It's a time of your life where you don't know everything about yourself yet. He's trying life out. The staff let him take the time to decide what he likes and doesn't like. He's got some routine to his week, and then sometimes he's doing something different or special.

Sheena, Alistair's sister, took him to see the Black-Eyed Peas which he really enjoyed, and they went to a Kylie concert together. Alistair and I split the cost of Sheena's ticket for a birthday treat. Our family love celebrating birthdays! Alistair likes looking at pictures of his 21st birthday where he had a disco with his family and friends. He loves going to concerts and ceilidhs and listening to bagpipe music. He has been to Braemar and Balloch Highland Games. His carers or myself arrange these trips. Alistair also loves going to the World Pipe Band Competition in Glasgow. Chris thinks he might like Karaoke but we haven't tried that yet. His team are still finding out where he can go in a wheelchair.

At school, people went out in groups, in a special bus or on the train.

Since moving into his own house, Alistair has been able to use a people carrier owned by The Thistle Foundation. I drive or one of his carers does. This has given Alistair the freedom to visit Blair Drummond Safari Park, go on holiday to Keilder and visit his family at Christmas. He also uses taxis or the train. He would like his own car some day.

His latest project is to have the back garden slabbed for a barbecue area and invite people round. Everybody knows everybody here. Alistair had a housewarming when he moved in. At the time some of the kids who came were just little kids. Now they're growing up and making their own decisions. One of them recently asked Alistair to the bowling for his birthday party. To start with they all wanted to help.

They saw Alistair as someone in a wheelchair. Now he's just the chap who lives next door.

The best thing is the independence and Alistair can only have this with support. Without it he would be in institutional care. We looked at that. We know now that it isn't what he needs or should have. It isn't just about 'support'- it's the quality of that support.

We went back to Stanmore for a school fete. Alistair was pretty miserable that day. I think he was afraid that the return trip meant he was going back.



I'm a bit of a coffee connoisseur. I can tell you all the best places for a good cup of coffee and a nice cake.

MR BOYD

“The coffee connoisseur”

Mr Jim Boyd is part of a close extended family, and has always been close to his cousin Sandra. Together they told his story.

Sandra

Jim had an ordinary childhood. We more or less grew up together. We used to fight, but he always stuck up for me, as I did for him. His dad was a printer and the kind of man that would have written to the Prime Minister if he had thought it would help his son. Jim was never shut away the way some people with disabilities were then. He was included in everything we did. His mum and dad had to pay for all the things Jim needed, like his callipers and the taxis back and forward to school.

Jim lived at home with his mum and dad until he was fifty. He went to the Anchor Centre in Paisley and he loved that. When Jim's dad died his mum couldn't manage and Merchiston was the only option. Every time his mum visited there she had to go to bed afterwards. She couldn't cope seeing him there. She died two months after he moved there of a broken heart.

I'm amazed Jim survived the 15 years in Merchiston. He went from a family home to a 'cottage' of 33 people. There were 9 people in each bedroom. We helped to get money for a fireplace and to put a border up around the communal room. The staff used the patients' quiet room to have their breaks and eat Chinese.

We insisted that Jim continue going to the Anchor Centre in Paisley. It wasn't just so he could get out. We felt he would be safe there. We could trust the staff and they would have a better idea what was going on. They supported us through difficult times. It was very unusual for a patient to go out during the day and Jim paid for that. The staff punished him, getting him up first in the morning only to wait for an hour and a half for the bus to come.

I regularly got calls saying Jim was being violent and crawling about trying to grab people's ankles. I always knew what staff would be on before I got there. When Jim didn't do what he was told, they threatened that he wouldn't get to the Anchor Centre. That's what made him do it. When I arrived I would hear him shouting. When he saw me his eyes would be wide and he would clamp his hand over his mouth. He came out of Merchiston with a very negative reputation but his reputation was a false one.

Jim

I almost take it for granted now that I have choices. In the morning, do I want a bath or a shower, what will I wear, what will I have for breakfast? I always watch Phil and Fern in Good Morning. I like Fern. Otherwise I like the radio. I've had a lot of good times since I moved here.

I quite liked having people around me at Merchiston but I don't miss it. I didn't like not being listened to, having set meal times and nothing to do. You had to get up at the crack of dawn and go to bed early. I'm retired so I like to stay up late watching the telly and have a long lie in the morning. I've got good neighbours here - Vince on one side, and Rena on the other. She's just become a granny and she's always looking out for me. I've got to know a lot of people in the town now, so they stop and have a chat. I'm a bit of a coffee connoisseur. I can tell you all the best places for a good cup of coffee and a nice cake. My regular is the Coffee Bean. I know most of the staff in there and it's a good place for people watching. I go in with one of my support workers. We take it in turns to buy the coffees.

The family come round here a lot. We had a party for my 70th at the Loch Fyne Hotel. All the family came and they stayed over. It was my treat - I wanted it to be my treat. We had two tables - the table that got the wine enjoyed it the best! The other table didn't get any because the hotel had run out of wine glasses.

I've been on a holiday to Spain - age 69, first time I've been abroad. Two of my personal assistants came with me. We were at the beach, watching the folk on the sand and in the sea, but we couldn't work out how to get my wheelchair over the sand. Tom and Jacqueline thought about it and explored the different parts of the beach till they found a bit where you could go over grass and get much nearer to the water. So we got there and I sat in a chair at the edge of the sea with the sand between my toes and the waves coming over my feet. Lovely!

The family come round here a lot. We had a party for my 70th at the Loch Fyne Hotel. All the family came and they stayed over. It was my treat - I wanted it to be my treat.

At Merchiston they said I liked swimming, but I don't. I like the sea though. When I was wee we used to take a run to Largs. I got dressed smart and walked along the front with Mum and Dad. We go for runs there now and it brings back happy memories of the most important person to me - Mum. My main hobby is going to the theatre, especially musicals. I've been to see Miss Saigon and My Fair Lady. We were out yesterday but it was a bit of a miserable day and we ended up in Strathclyde Park and discovered the circus was on - that was good. But the ice dancing was a different story. I had my hands over my ears and had to blow on my hands to let Tom know it wasn't my cup of tea. He knows me well enough to get the message.

Sandra

I'd heard rumours that there were to be 10 people moved out - 'the easy ones'. Given Jim's reputation I was surprised to find he was one of them but then I discovered that because of his age, they'd ticked the box saying a nursing home would be suitable. There were endless meetings and fights, but luckily Jim had an advocate and he agreed with us that a nursing home wouldn't be suitable. We were really worried about what would happen, but it was better to hold out and see what materialised.

Pulling together the introductory package took time, but it was worth it. His mum and dad wouldn't believe what has happened - his own home, his own staff. Jim is back to the Jim we knew. His family don't worry about him any more. My dream is that this continues for as long as Jim is able to enjoy it.

BENEATH AND BEYOND

Having a shave in the morning, going to Mum's for tea, paying the bills, listening to a CD in the car, going out clubbing - the chores and small pleasures of everyday life. Set against individuals' experiences before they moved to their own homes, they are remarkable achievements of extraordinary people gradually discovering and recovering ordinary life from a base where few expected it to be possible.

LOST HISTORIES AND FALSE REPUTATIONS

When plans were being made for Jim (page 21) to leave hospital, there was pessimism and resistance to this from health professionals. Similar attitudes prevailed about others, predicting damage to property and violence towards staff. Some people could only leave institutional settings hospital providing they received (paid) round the clock, one to one care. Five years later, Jim has support for only part of each day. He has tried one job and is actively looking for another; he does messages for a neighbour; he goes to the local café most days for his breakfast, on his own; and at his own request he has no support after 5.30 pm every day.

Mr Boyd's (page 53) frustration with his life in hospital led him to throw himself out of his chair and grab people by the ankles. Others expected that, at age 68, he would need constant and intensive support to live in the community. His history of ordinary living with family in the community and sense of self were lost in hospital. From the day he left hospital for his own home he has not once thrown himself at anyone. He is once again a respected and loved older gentleman.

The changes in people's lives are such that it is difficult, almost impossible, to match the labels and reputations to those now living full, ordinary lives. The Thistle Foundation and others made a substantial emotional and financial investment in developing housing and support, staking this on their belief in the potential of people not given opportunities. They knew that with individualised approaches and dedicated continuing support, it would be possible to work beyond

labels and reputations. Family members and advocates also helped people to have a voice in challenging assumptions.

THE MULTIPLE LOSSES OF SOCIAL EXCLUSION

Several people didn't want to talk about their life before, finding it too painful or upsetting. It was not difficult to get meaning from silences or apathetic responses on particular subjects. Some clear statements indicated that these were 'no go' areas. Some stories included discomfort and confusion about the past, even anger and bitterness.

These stories, the great losses identified by Wolfensberger (1972, 1998) in his writings about social role valorisation and people devalued by society, are recognisable. People were multiply rejected - by family, by schools, by health and social care professionals. Some were stigmatised in deviancy roles, for example, 'ankle grabber'. They failed to develop a sense of self worth - one person felt "it would have been better if I had not have been born". They lost opportunities for education and experience. Some, such as Tommy, even lost the history of why they spent most of their lives in institutions. Families were split up and devastated, "my heart was broken". Communities lost people in not realising the contributions they were missing. All were damaged as a result. In some of the stories we can hear that these wounds remain. They may never fully heal.

"The sort of society in which there is no risk is neither achievable nor desirable."

(Scottish Executive, 2006)

Support workers observe that only now are the sources of these hurts being revealed - to people who have quietly supported the person's growing confidence with the routine and shared the excitement of achieving the extraordinary. The impact and necessity of trusted supporters sensitive to revelations and able to respond to these, is significant.

ELEMENTS OF PERSONALISED SUPPORT

We noticed some common themes and key points at the heart of these journeys.

Individual and autonomous staff teams

Some of the people who tell their stories here aspired to supported independent living, achieving the same quality of life as their non-disabled peers. Others had not even

considered it. All, in different degrees, faced the prospect with apprehension as well as hope. David Crawford, Head of Social Work at Renfrewshire Council, remembers the strong fears of some individuals, their families, hospital staff and consultants, that the moves would “lead to miserable, lonely and neglected lives.”

With the individual, their family, professionals and other people’s knowledge, The Thistle Foundation built up proposals for individual care and support services. Most of the individuals and their families put together staff profiles for their own team; commented on the decoration and design for their new home and thought about special equipment that would be needed or which would make life easier. Over time needs and aspirations change and they can negotiate changes to how they are supported, to develop in new areas and to choose their own staff. Trust, pride and self-esteem started to grow from the nature of the early approaches.

“We knit the service and the team to fit the person”
Margaret McMahon

Where support is designed with, and to fit, the individual - rather than the individual fitting into a service - then it is easier to flex and adapt this to respond to changing needs and situations. Experience shows this is also more cost effective and it has been critical in supporting people to develop and lead meaningful lives (Duffy, 2003; Duffy, 2005). Reductions in medication and incidence of depression are clear benefits to the supported people, and in terms of wider costs.

Over the last five years, (responding to the needs of people supported) The Thistle Foundation has changed its organisational culture and structure to provide individualised and autonomous services. Each person has his or her own clearly defined staff team. Some people indicate an increasing sense of control and a continuing need, for the moment, for support in exercising this. It may take some time for this to develop or become established when for so long most people had no control over their lives.

The invisible touch

No-one - not a single person - talked about support received

in terms of people providing 'care' or personal care for them. Yet clearly many people in these stories have significant physical and health care support needs. Their supporters also assist with day-to-day essentials like getting up, dressing, bathing, eating, managing intimate tasks and managing health care.

This is necessary to have a life, but it is not the focus of these lives. 'A good life' is going to the football, seeing your family, sharing time with friends, retail therapy, having a bubble bath, the best coffee in town, trying something new, planning a holiday or working towards a personal challenge - from learning a language to going out at night on your own. From these accounts, support for these areas is implicitly highly valued, from what people here have chosen to speak about. They talked extensively about their everyday choices and increasing their own experiences and skills. Support staff use considerable creativity in thinking about how people can be supported in this. Many seemed almost to gulp down new experiences to make up for lost time.

Choice, control and opportunity

Most spoke about how much they valued their freedom, relishing their independence, but they are still finding their voice to do so within safe relationships. Some people had learned that having opinions, insisting on something important or complaining, could have negative consequences. It is taking time to believe otherwise. Some are still learning that they are allowed to express their dislikes.

People spoke with pleasure about making choices and controlling outcomes, especially in small things like when to get up and go to bed; what and when to eat; what to wear. Five years on, this is still a novelty for most. They are not yet taking for granted the impact it makes on their quality of life. For 65 years, Tommy did not have these simple choices. For 40 years, Jim had almost all personal care carried out for him. He was not given a choice about what he might learn to do himself. His growing self-esteem and confidence in the range of things he can now do and learn is palpable.

Taking risks

Vince's decision to get married; Jim's decision to stay on his own overnight; the decision that Barry did not need carpets on the wall; Tommy's making friends with someone who supports him - these all involve risks. Connie spoke of sadness about the impact on her relationship with her family when she decided to move to Renfrew and marry Neil. Some choices have positive and negative consequences.

The Thistle Foundation recognises the difficulties of changing its culture to one that gives power and control to the individual, and the tensions that can arise from different perceptions of risk by different people and agencies. The stories illustrate how the desire to remove risk can undermine personal growth. Barry was not allowed to go with others on day trips from the hospital; Neil was discouraged from making friends; Jim was not allowed to shave himself.

Most of the people here had never had the opportunity or freedom to take risks, and they needed support to know what their choices were, to understand them, to assess and manage the risks that may be involved. Those around them have to balance their duty to protect with acknowledgement that taking risks, making mistakes, and making difficult choices is part of life.

Rediscovering family and developing natural networks

Many people spoke with particular satisfaction and pride about their relationships with family members and friends: Barry delighted in being part of the family table; Alistair shared the cost of his sister's concert ticket; Laura's ordinary welcoming of family; Mr Boyd's ability to give hospitality and to take a rightful place at a party. People are married or in the process of marrying. Having experienced rejection and exclusion since childhood Vince, Neil and Connie are deeply emotional about having found this level of intimacy with another person. This was beyond aspiration. As Vince put it, "I never thought I'd see this day." Their new status changes the dynamic and focus of the support they need and want.

Family members spoke about 'being involved'. Others referred to the casual and natural supports that have been fostered with family, friends and neighbours: "Mum and Dad dog sat for us when we were on holiday". These are often relationships that had been all but lost. Families had little or no trust in a system they perceived had stolen their relative from them. The strongest and fondest memories were when people spoke about or showed DVDs and photographs of family members. For Barry and Mr Boyd, being relocated within a family has given them back a core part of their identity.

The recognition and inclusion of informal support and care provided by family and friends is integral to person centred support. Opportunities are created for involving family and friends, recognising their value and the importance of these relationships to individual wellbeing. The satisfaction gained from mutual contribution also emerged in several stories - Jim fetching the paper for his neighbour, Laura reassuring her support worker, Vince and Marion's mutual support, Connie's job. This is still in its early days.

Relationships with neighbours and friends were a common theme. For many, friends are those they knew while in Merchiston or close family. Without a background of community connections, the development of friendships and new connections with friends and family of paid supporters is, in some cases, a natural consequence of matching staff to individuals. The Thistle Foundation recognises that this brings different challenges and risks, which need to be assessed and managed comprehensively and carefully to keep everyone involved safe and protected.

This is new ground and it does not sit comfortably with the traditional approach to organising social services based on the 'professional gift model' (Duffy, 2005). This models the relationship between individual, purchaser and provider as 'needy person', one way recipient of the 'professional provider' services to meet assessed needs and relegating the community to tax payer for those services. Yet as the Scottish Executive's 21st Century Social Work Review (2006) concludes, this is not a sustainable approach. The 'citizenship

model' incorporates a mutual relationship between an individual citizen, those purchasing and providing support and the community. This is a challenge, with greater uncertainty and potentially more risk, and greater benefits for individuals, communities and society.

Present in ordinary places

Renfrew is a relatively small town with a small town centre within walking distance from where people live. It is the type of place where it does not take long to become a familiar face. Many people mentioned and valued their acquaintance with other shoppers, shop assistants, bank tellers and Post Office staff, and the chats and "hellos" from passers by. They now contribute to the local scene and economy.

Most people also spoke of longer journeys - the opportunity and freedom to explore places and experiences previously not possible. For Ian, Tommy and Lorraine, ownership and control over transport was one of the best and most liberating aspects of their new lives. Achieving this has required independent access to and control over money, and access to drivers.

For some people, their social circle focuses on what they know and like - the ENABLE club, the SPRED group, the Anchor Centre, friends from hospital, paid support workers, family and neighbours also supported by The Thistle Foundation. However a few people are beginning, with support, to spread their wings into the wider community, moving from physical integration to social integration i.e. more than 'say hi relationships' (O'Brien, 2006).

Well-designed and integrated housing

Designing housing from scratch meant that properties could be designed to meet individual needs, incorporating the space and technology to allow more independence. Almost everybody supported uses a wheelchair. Several people had been hoping for some time, even before Blythswood closed, for their own home, but the lack of housing suitable for wheelchair users was the biggest barrier. Where two wheelchair users want to live together or marry, they despair of finding a house large enough to

accommodate them. Here there are no such barriers. This is not to say that individuals will never need or want to move. As people mature, their housing needs and wants change.

One of the mixed developments is designed around a courtyard with limited private front space and small back gardens for the family houses. The design encourages people to sit out at the front and children to play in the street. "Everyone knows everyone here" was a common remark. One person commented on the wider benefits of the integrated development - "I hadn't really thought about it before, but the mixed neighbourhood is good - it's good for the people supported by The Thistle Foundation and it's good for the neighbours and the children."

THE TRANSFORMATIONAL JOURNEY TO PERSON CENTRED, INDIVIDUALISED SERVICES

The Thistle Foundation's vision that people with disabilities should be supported to live with their families in ordinary communities, has been sustained. However, an intertwined journey with those it supports has transformed the culture and approach for achieving this.

A person centred approach has a base assumption that the driver of the services is the person requesting or requiring support (not the agency providing the service). The service is uniquely designed to be responsive to individual needs and desires, using truly individualised, natural and creative supports. (Bradley 1994). This is founded on certain core principles and attitudes:

- People need close, right and real relationships, with people who actively listen and who do not hide behind a professional façade.
- Individuals have different strengths, interests and talents to use in achieving meaningful goals, and are to be positively regarded.
- People have a right to a real life i.e. to choose their own home; who they live with; who supports them; what to do and when; to have a job; to have family and friends on their terms; to take part in the community; to be healthy and safe; to try new things and take risks.

A good life consists of “home; family and friends; being accorded dignity, respect, acceptance; a sense of belonging; an education; and the development and exercise of one’s capacities; a voice in the affairs of one’s community and society; opportunities to participate; a decent material standard of living; an at least normative place to live; and opportunities for work and self support.”

(O’Brien, 2006)

Researchers in the US (www.llr.cornell.edu) observe that system centred services are fundamentally incompatible with person centred services. To put these principles into practice requires culture change on the part of commissioners and providers of services; ceding of power and control to individuals and the acceptance and management of associated risks. To provide tailor made support for the people in these stories meant The Thistle Foundation needed to change in culture, leadership and organisational structure. The stories reveal some of the ways in which its services and practices were transformed to align with person centred values and principles.

WORKING TOWARDS INCLUSION

The people here recovered some elements of ‘a good life’ and are starting to find the others. However, as O’Brien (2006) states, achieving inclusion goes beyond this. It means the integration in society of people who have been and are at risk of being devalued with those who have not had this experience. This is more than having choices, being present in ordinary places and having a good time at disabled clubs. It means being invited to take a role in ordinary community activities, extending personal networks and relationships and discovering “ways through [the] walls” that divide people with disabilities from their fellow citizens.

O’Brien does not minimise that mutual relationship building is a major challenge requiring thoughtful and sustained support. The foundations are in place in the circles around people (paid and unpaid) who have built up their appreciation and knowledge of the individual’s qualities and strengths and are well placed to build the capacity for others to recognise and welcome these contributions.

Enabling supported living and inclusion where there has been years of exclusion is not easy or quick. Taken step by step (in Laura’s case almost literally) the achievement of these people in 5 years has been great. They are starting to sense what is possible - reaching their own potential. This is not something that can be halted, or not without wounding in a different way (perhaps by limiting people to ‘inferior community living’ [Kendrick, 1997]). Protecting the individuals’ development,

fostering the personal networks and ensuring further growth is a significant responsibility and challenge for everyone involved.

BEYOND

It takes dedicated, individualised and prolonged support to regenerate devalued and damaged people and communities. Building self-esteem, developing skills and capacities, overcoming problems and obstacles is substantial work. After spending between 10 and 65 years in care, these people have made an extraordinary journey in less than 5 years. They are at different places on their journey and getting there by different means, with support that recognises and celebrates their individuality. Some have clear ambitions to go further and require support to get there. They want jobs. They want to do more and more things independently. They want more friends. They want successful marriages. They want never to go back. They want to tell others to dream too. They “don’t want to miss a thing”.

REFERENCES

- Bradley,V. (1994) Evolution of a new service paradigm. In Bradley,V., Ashbaugh, J., & Blaney, B. (Eds), *Creating individual supports for people with developmental disabilities*
- Duffy, S., (2003) *Keys to Citizenship. Paradigm*
- Duffy, S., (2005) Individual Budgets:Transferring the allocation of resources for care. In *Journal for Integrated Care*,Vol. 13 (1)
- Griffiths, R., (1988) *Care in the Community, an agenda for action. HMSO*
- Kendrick, M., (1997) The Leadership Challenge of Service Quality. In *Interaction*,Vol 11, Issue 1, 1997
- O'Brien, J., (2006) "to interact with non-disabled persons to the fullest extent possible": Perspectives on "Most Integrated" services for people with developmental disabilities. Syracuse, NY:The Center on Human Policy
- Scottish Executive, (2000) *The same as you? A review of services for people with learning disabilities*
- Scottish Executive, (2006) *Changing Lives. Report of the 21st Century Review of Social Work and Ministerial Response*
- Simmons, J., (2000) *Listening to Stories: Book Trade Narratives. In National Life Story Collection Issue 5*
- Sinclair, J., (2005) "The Impact of Stories". In *The Electronic Journal of Knowledge Management* Vol 3 Issue 1, pp53 - 64, available online at www.ejkm.com
- Wolfensberger, W., (1972) *The principle of normalisation in human services. Toronto: National Institute for Mental Retardation.*
- Wolfensberger, W., (1998) *A brief introduction to Social Role Valorisation: a higher order concept for addressing the plight of socially devalued people, and for structuring human services. (3rd ed.). Syracuse, NY*

THANK YOU

We are grateful for the hard work and courage of everyone who has told their story here and for their patience with our efforts as their 'ghostwriters'.

We would also like to thank the following people for helping us to hear the stories, organising and supporting interviews and photographs or providing background information and context: Margaret McMahan, Andrea Robb, Sally Cameron, the personal assistants and support workers in individual staff teams, family members and David Crawford.

Editorial advisors: Diana Paton, Linda Burnett, Margaret McMahan.

Between December 2000 and June 2001, 14 people began new lives - a regeneration process of discovery and rediscovery. They moved from institutional care for people with learning difficulties and physical disabilities to their own brand new homes in two ordinary neighbourhoods in Renfrew, Scotland. They had spent between 10 and 65 years in different institutional environments - an average of 28 years each - and a combined total of 339 years in care. All, in unique ways, needed and need support to live full and included lives, to participate in and contribute to their community and to achieve their potential.



THE THISTLE FOUNDATION
WORKING TOGETHER FOR AN INCLUSIVE SOCIETY

This is their stories.

The Thistle Foundation
Niddrie Mains Road
Edinburgh
EH16 4EA
T.0131 661 3366
E. enquiry@thistle.org.uk
www.thistle.org.uk

Charity number: SC 016816



in Control
4 Swan Courtyard
Coventry Road
Birmingham
B26 1BU
www.in-control.org.uk