

# Cheshire Smile

JANUARY 1999

INTERNATIONAL

## Golden Moments

Mixing business with pleasure at World Week '98

**Plus**

Workability and Self-Reliance

Enabling disabled people to become independent

A mountainous challenge

The lengths some people will go to to raise money for our services

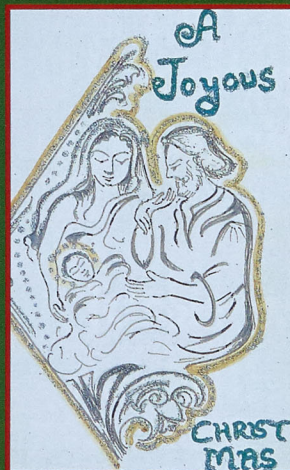
*Creating opportunities with disabled people*

**LEONARD CHESHIRE**

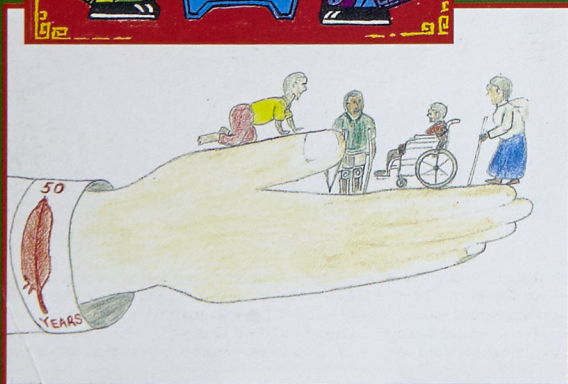




# Goreti's Christmas design to travel across the world!



GORETI ROCAS from Portugal has won this year's LCI Christmas competition. Goreti, whose depiction of the Three Kings in wheelchairs caught the imagination of the judges, wins an all-expenses paid trip to a Cheshire Home in the UK. Mr H. Qiming of the Wuhan CH in China was awarded second place and the runners up from the many excellent entries we received were Prakriti Sen Gupta from Tollygunge CH, India, Jacque Lunga, Kolbe House, Zambia, Dolly Mazumder, Burnpur CH, India, Tukku Chakroborty, Burnpur CH, India and Bernard Kasarre, Katalamwa CH, Uganda.





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INTERNATIONAL

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Leonard Cheshire promotes the care, general well-being and rehabilitation of people with physical and learning disabilities, through more than 320 services throughout the world. Cheshire Smile International is produced by Leonard Cheshire, 30 Millbank, London SW1P 4QD, England. Tel: 0171 802 8200. ISSN 1374-0920. Copyright Leonard Cheshire 1998. Contact: Judith Riley. Printed by Manor Group Ltd, Unit 7, Edison Road, Highfield Industrial Estate, Hampden Park, Eastbourne, East Sussex BN23 6PT. Opinions expressed in this magazine do not necessarily reflect the policy and views of Leonard Cheshire. Advertisements do not necessarily imply endorsement by Leonard Cheshire. All rights reserved. Unauthorised reproduction in part or whole is prohibited without prior written permission. MSS, photographs and artwork are accepted on the bases that Cheshire Smile magazine and its agents do not accept liability for loss or damage to the same. Registered charity number: 218186



# INTERNATIONAL NEWSDESK



**Katpadi chairman Mr P. S. Rajagopal Naidu and Worth Trust consultant Mr D.K. Oza pass Mr Pradheep Ydhav a lighted candle with which to light the Kuthuvilakku to launch the workshop for disabled women (see story below).**

## The skills to earn a proper wage

DISABLED women from the Katpadi district of Gandhi Nagar in India are being given the skills to help them to go out to work and become independent, thanks to a partnership involving their local Cheshire Home.

Katpadi CH has teamed up with the Self Help Association for Rural Education and Employment (SHARE) and the Workshop for Rehabilitation and Training of the Handicapped (WORTH) to provide a six-month residential training programme.

The women are learning to make palm-leaf products and are also learning one other skill with the aim of becoming economically self-reliant.

Mr Pradheep Ydhav, the project director of the District Rural Development Agency, said the programme's success owed much to the combined efforts of the different organisations and the way they had worked together.

"With the guidance and combination of all the organisations working together on this project, I am sure that on completion of training, these

women will be able to earn sizeable profits," he said.

## Contact the LCI office instantly!

LEONARD Cheshire International's office can now be contacted immediately – through e-mail.

The full e-mail address is [international@london.leonard-cheshire.org.uk](mailto:international@london.leonard-cheshire.org.uk)

## Television tribute to Ruth Shearman

ONE of the UK Cheshire Homes' most talented and creative residents, Ruth Shearman, has died at the age of 26.

Ruth, who lived at the Manor CH in Brampton for the last six years of her life, achieved national recognition for her work as a writer.

Her thought-provoking work "No Chair For Donna", about an able-bodied woman who experiences isolation and discrimination in a world of disabled people, was featured in a recent edition of Cheshire Smile International and has just been filmed for television. It is expected to be shown on a

British network within the next few months.

## Change reflects modern attitudes

A CHESHIRE project in Canada has changed its name to drop the word "care" from its title.

The change came after the project's marketing committee decided the name Tobias House of Toronto – Attendant Care Incorporated was confusing, inappropriate and no longer relevant.

The project's latest newsletter reveals, "over the years concern has been expressed by our consumers that as part of independent living concept, Tobias does not 'care' for them, but does assist in meeting their individual needs".

As a result the project now enjoys the much shorter name of Tobias Incorporated.

## The man who guided Bangladesh

THE man instrumental in establishing and expanding the Bangladesh Cheshire Home in Dhaka has died after a short illness.

Justice Badrul Haider Chowdhury had been chairman of the home for 18 years of its 23-year history.

When he became chairman, the home consisted of two separate rented buildings, each accommodating 14-16 residents. Within the next year, he worked with vice-chairman Abdul Malek and committee member Abdul Salek to develop a new home to accommodate 50 residents in

Uttara Model Town.

In 1992, Justice Chowdhury was instrumental in opening the Leonard Cheshire High School, which also operates as a cyclone shelter, in Char Clark, District Noakhali, following the cyclone the previous year.

## Programme opens in Pakistan

A NEW Cheshire project has been launched in Pakistan.

The Tamir Cheshire Community Programme, based in Faisalabad, is the first LC project in the country and further details will appear in a forthcoming edition of CSI.

## Diana fund awards £1m to Park House

LEONARD CHESHIRE'S Park House Hotel, the birthplace of Diana, Princess of Wales, has been awarded £1 million by the Princess's memorial fund.

The grant is an endowment fund which will ensure the future of the hotel, which lies within HM Queen's Sandringham estate in Norfolk, England, as a country house hotel for disabled visitors.

It will also enable the development of a day care centre and domiciliary care service, based at Park House, for disabled people in West Norfolk.

The hotel, given to Leonard Cheshire by HM The Queen in 1981, had faced closure – the cost of providing high levels of support meant the rate at which guests could be charged did not cover running costs.

The Princess, who was born in one of the bedrooms, maintained her link with the property throughout her life.



■ A region is born – Southern Africa's inaugural meeting



# Memories prove the candle still burns

*'Sorrow's shadows cloud the moon,  
The world abruptly turns,  
The man who lit the flame has gone  
But still the candle burns.'*

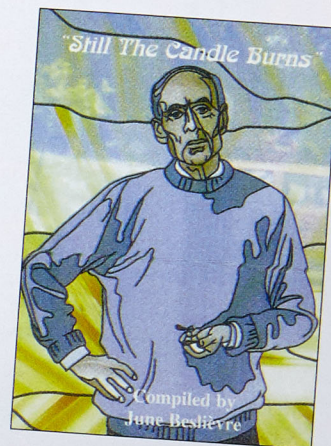
These words of west-country poet David Prowse, written at the time of Leonard Cheshire's death, were the inspiration for the title of the book *Still The Candle Burns*, a collection of reminiscences and reflections on our founder.

The anthology, compiled by June Beslievre from the Jersey Cheshire Home, has received widespread plaudits for its easy-to-read and absorbing content, presenting with accompanying photographs and other interesting highlights.

There are fascinating contributions by people from all walks of life throughout the worldwide Leonard Cheshire organisation, with many intimate and affectionate insights and amusing stories showing Leonard's subtle sense of humour, and the way our founder's spirit shines through.

Described as a gem of a book about a gem of a person, it is recommended for everyone who knew Leonard Cheshire and – especially in this Golden Jubilee year – for those who have not had the opportunity to know him.

The anthology, priced £7.99 plus postage and packing, is available from Jersey Cheshire Home (Book Order), Rope Walk, St Helier, Jersey, Channel Islands, JE2 4UU.



## New region for Southern Africa

REPRESENTATIVES from nine countries in Southern Africa have formally established the area as a new Leonard Cheshire region.

Delegates from Botswana, Lesotho, Malawi, Mauritius, Namibia, South Africa, Swaziland, Zambia and Zimbabwe, which have 38 Cheshire services between them, set up the new structure in Johannesburg earlier this year.

As well as consolidating work in their own individual countries, members of the region are investigating the possibility of developing services in neighbouring countries including Angola, Mozambique and Madagascar.

## Watercolours help to buy vehicle

THE artistic talent of UK chairman Sir David Goodall has helped to provide a much-needed vehicle to serve two Cheshire Homes in India.

Sir David's book of watercolours 'Remembering India', which was featured in *CSI* January 1998, has raised more than £5,000 for the Tollygunge CH and the Serampore CH, both of which are in the Calcutta area.

Sir David painted the 51 watercolours in the book during his four years as the country's British High Commissioner between 1987 and 1991.

The chairman was presented with a cheque for six lakhs of rupees by Sir Martin Jacomb, chairman of Prudential Corporation, the book's sponsors, following a lecture

which Sir David gave at London's Nehru Centre.

'Remembering India' is priced £14.99 sterling or US\$25, and is available from Scorpion Cavendish, 31 Museum Street, London, WC1A 1LH, England. All profits from sales will continue to be donated to Cheshire Homes in India.

## Is it time for a change of name?

CAN you think of a new name for Cheshire Smile International?

As the 21st century approaches, we are looking for a fresh approach to publicising our work across the world into the new millennium and beyond.

One way we can do this might be to rename this magazine.

While the name *Smile* has served us well over many years – the magazine was first published 43 years ago! – the work of Leonard Cheshire across the world has grown and developed to such an extent that it might be time to think of something which more specifically, and instantly, sums up who we are and what we do.

What do you think? Do you think it's time for a new name? What do you think the magazine should be called?

Please send your ideas to Cheshire Smile International, Leonard Cheshire, 30 Millbank, London SW1P 4QD, England.

Who knows, people all over the world might soon be talking about a name you have suggested!



People are enabled – wherever you see this sign

ONE of the greatest successes in a Golden Jubilee year of successes has been Leonard Cheshire UK's Enabled campaign.

The advertising campaign, based on the familiar orange badge used by UK disabled drivers, has swamped national and regional newspapers and magazines and advertising hearings and has attracted much interest from radio and television news programmes.

As a result the awareness of Leonard Cheshire and its work among the UK general public has already increased by ten per cent – and the figure is rising.

The badge, of course, is instantly recognised as a symbol representing disabled people, but our campaign emblem carries one fundamental difference – instead of the word "disabled", the Leonard Cheshire campaign emblem reads "enabled".

A number of variations, including depictions of a person holding a key and a person playing a saxophone, have also grabbed people's attention.

The symbol is now being widely used in our promotional materials, such as leaflets, posters and t-shirts.

The campaign has now moved into its second stage – adverts which appeared in the UK during the British summer were concerned with raising awareness and linking the name Leonard Cheshire with disabled people. The second phase, which will continue through the autumn, will focus more on asking people to support our work with donations.





# A proper job, a decent living

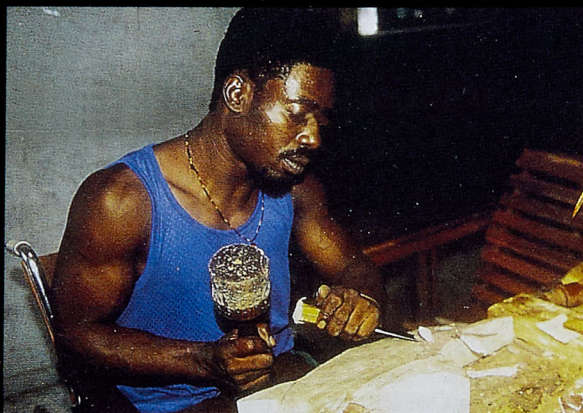
**G**OAT-REARING, hair-dressing, computing and pottery are just some of the skills that disabled people across the world will learn so they can earn their own living.

The International Self-Reliance Programme has just awarded grants to the first successful applicants and while the schemes are diverse, every applicant has the same goal – to achieve a level of financial independence.

"We awarded seven grants to individuals and more to Leonard Cheshire services," says Assistant International Director (Training and Development) Joanne Martin.

Those who were unsuccessful this time are being supported by their region and the LCI office in London to enable them to process a stronger application for the next round of grants, for which the closing date is March 1999.

"We anticipate many more applications being received for the next round and these applications will be of a high quality," says Joanne.



"As time goes on, the programme will become more established."

Among the grants awarded to services are:

- £528 for a goat-rearing training scheme and co-operative in Zimbabwe.

- £7,000 for equipment for a workshop in Madras, where disabled people are learning skills in plastics and paper packaging. Once equipped with the skills and confidence, they will be assisted to access similar types of employment outside the home.

- £7,400 for a training centre in the Philippines. The money will be used to buy a kiln and build the structure to house it. The centre already carries out a number of programmes but wants to introduce pottery as such skills are lacking in the local employment market.

- £5,000 to the Ghana CH where disabled people are starting training in hair-dressing and batik fabric design.

- £7,500 to a Cheshire project at the Chief Dlamini CH in South Africa where disabled people are already learning a variety of skills, but the centre wants to introduce business skills training, computing and tailoring.

- £2,050 to Bo CH in Sierra Leone for equipment to enable training in typing, basic electronics and tailoring.

"If I have my own tailoring shop and a good sewing machine, I can stand on my own feet and be able to earn more money," he wrote in his application.

"This will help in improving the status of my life and my family."

Togarepi Chimbaranga moved to Masterton CH in Zimbabwe after a gunshot wound left him disabled.

He is already a keen amateur photographer and helps a local professional, but the SRP grant will help him to start his own business.

"My plans include acquiring as much knowledge as I can and developing my photographic project to a productive standard that is unique," he wrote.

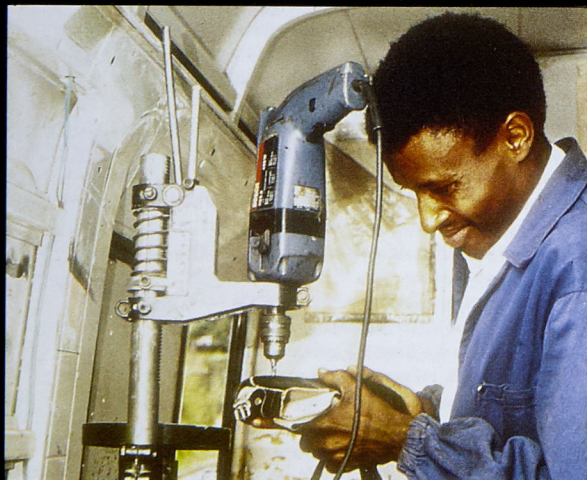
"This will help me to obtain a home that is mine."

Other successful individual applicants include:

- Dennis Pomo from Zimbabwe, who intends to open a tuckshop

- Funny Rusike from Masterton CH, Zimbabwe, who also wants to open a tuckshop

- Adama Mamanda from Bo CH, Sierra Leone, who wants to open a shop to sell food and drink but will also receive moeny for a sewing machine. This will enable him to make use of his tailoring training to make things to sell in the shop.



■ The grants will enabled disabled people to learn new skills, enabling them to become financially independent.

**G**ULZAR NISAR is 19 years old and his legs are paralysed after he contracted typhoid when he was a child. Although Gulzar, who lives in Faisalabad, Pakistan, has learned tailoring skills, he could only use them when his mother was able to go out and get him some work.

Now, having been awarded an ISRP grant, he will have his own premises.

If you would like to find out more about the International Self-Reliance Programme, contact Jo Copsey or Mark O'Kelly at Leonard Cheshire International, 30 Millbank, London SW1P 4QD, England. If you would like to help to raise money to help fund the ISRP and give more disabled people across the world the chance to become independent, please contact Catherine Lightfoot at the same address.





■ **Chatting at Chiltern – UK Prime Minister Tony Blair talks to residents about their life in the home and his government's pledge to enable disabled people to play a bigger role in society**



## Tony Blair chats to Chiltern residents

UK PRIME MINISTER Tony Blair told Leonard Cheshire residents about his government's commitment to including disabled people in society when he visited our Chiltern home in Buckinghamshire, England.

Residents' representative Jill Morgan accompanied Mr Blair throughout his tour, during which he spoke of reforms which would "be looking to get disabled people

into work and provide help and security for those who cannot work".

During an informal meeting with residents over a cup of tea, he also talked about his own experiences of the difficulties of access for disabled people by telling the residents about an accident his mother-in-law had had. "It's all too easy to take things for granted," he said.

Mr Blair was asked to sign the Home's visitors' book – and described Chiltern as 'wonderful'.

## Wuhan CH celebrates



**WUHAN CH in China recently held a ceremony to commemorate weddings of disabled people to mark International Persons with Disabilities Day. Yu Fangsen, who is blind, is pictured receiving a cup of tea from Wuhan CH head of home Pei Hong.**

## 'The name of Leonard Cheshire is the best introduction we could have'

Assistant international director **ROGER BROWN** talks about his hopes for the expansion of LC International

I REMEMBER being very gripped, when I was 17 or 18, by Russell Braddon's biography of Leonard Cheshire, but then for many years, although I saw disability in many countries, I had no more than a vague idea of the work which he and his organisation were doing.

By the early 1990s, I had been a diplomat with the Foreign Office for more than 30 years and most of this time I had lived abroad, particularly in the countries of Africa, Asia and Latin America.

In 1992 I was posted to Brazil for the second time, on this occasion to Sao Paolo, and there I came into contact with the residents, committee and supporters of the Cheshire Home in Jaguare. I remember feeling nothing but admiration for all of them, and wanting to find ways to help them.

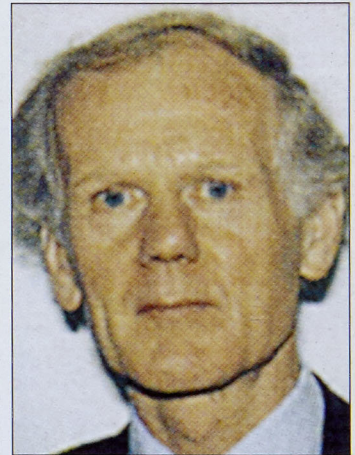
A month after I finally left the Foreign Office last November, a friend telephoned me from Brazil. She had seen in an advertisement that Leonard Cheshire International was looking for someone to help to develop services throughout the world, and particularly in Latin America.

When I was appointed to the job in May this year I felt that I had been incredibly lucky to discover, immediately, exactly what I wished to do in my new life. After so long as a civil servant, I couldn't help being a bit apprehensive about joining a quite different organisation, but I needn't have worried. The famous ethos, and the people now dedicated to carrying it on, immediately proved to be two of the best, and most supportive, features of the job.

I felt immensely glad to be able to participate in World Week, so soon after joining. The opportunity to meet so many members of the Cheshire family, from so many countries, all gathered together in London at what was generally agreed to be the best World Week ever, was a rare privilege.

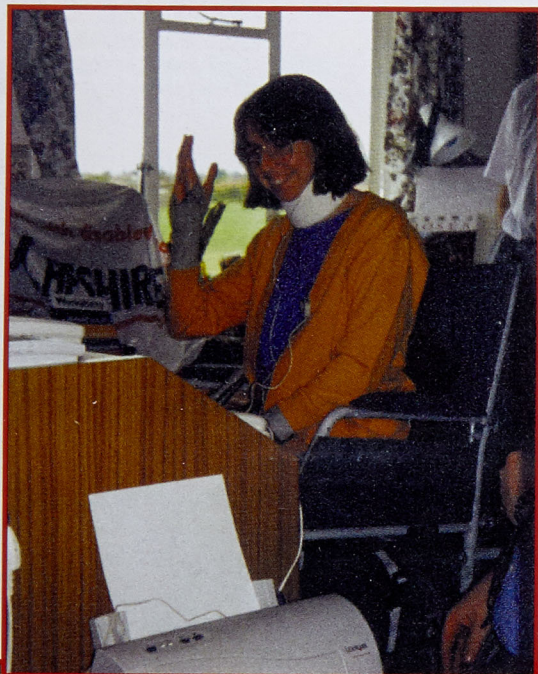
I don't for a moment think it is going to be an easy task to expand our activities from Mexico to Mozambique, Venezuela to Vietnam, but I hope that, in a few years from now, we shall be creating opportunities with disabled people in several new countries.

Wherever we go in the world, at least we know that the name of Leonard Cheshire is the best introduction we could have.





# Opening up the working world



**THE COMPUTER** revolution across the world over the last 20 years has changed our lives forever. Many of the things we do have become so much easier or quicker with computers that it's already difficult to remember a time before we had them.

For many thousands of disabled people, computers are more than just a convenience. Computers, particularly those with e-mail or hooked into the World Wide Web, remove some of the physical barriers that prevent disabled people from firstly gaining an education and secondly getting a job – and this can literally open up a whole new world.

Across the globe, Leonard Cheshire projects are enabling people to use computers as a way to compete with everyone else on a level playing field – at long last.



■ Susan Martell (above) and Janet Marker (top) become the first of 10,000 disabled people to switch on to Workability

**P**ENNY REYNOLDS decided she was fed up with watching soaps. It was 12 years since a tobogganing accident had left her using a wheelchair and five years since she'd had a job. It was time to get on with her life.

"I wasn't meeting anybody and I realised I was fed up with it," she says. "It was time to do something."

Today Penny is studying TV and radio broadcasting at college and her aspirations – "I want to be famous, as a radio or TV presenter" – are high.

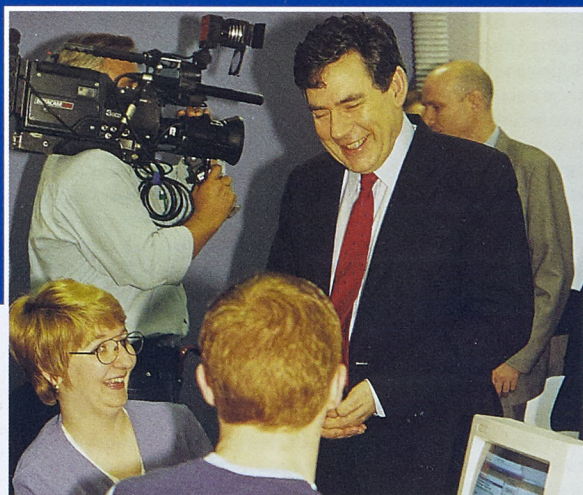
The difference to her life is her own energy and ambition – and a ground-breaking new project that Leonard Cheshire has launched in the UK.

*Workability* aims to provide 10,000 disabled people in the UK with computers and, crucially, training and support to help them enter what for many





■ **OPPORTUNITIES** – Marius Lotter tackles Summerstrand's figures (above) while below, UK Chancellor of the Exchequer Gordon Brown meets disabled people at the launch of *Workability*.



perfectly capable disabled people has been a closed world for too long – the world of work.

The scheme creates opportunities for participants whose individual disabilities currently range from repetitive strain injury and epilepsy to cerebral palsy, multiple sclerosis and brain injuries sustained in accidents.

The first 'intake' have already received their computers, Microsoft software and internet access which will enable them to receive online training and distance learning. A network of 'computer buddies' will offer participants employment support which will identify their abilities, provide help with job applications, interview and CV preparation and

offer 'Ready to Work' courses.

For Penny, it was just the boost she needed. "I did start doing some voluntary work but things really got moving when I heard about *Workability*. Computers are completely alien to me – I am a technophobe, but I'm learning. Using e-mail and the internet access that *Workability* has provided has literally opened up the world to me."

The scheme, with its aims to get disabled people recognised as a genuine, valuable element of the UK workforce, has been welcomed and backed by Tony Blair's Labour government. Chancellor of the Exchequer Gordon Brown, Education Secretary David Blunkett and then Social Services

## Computers are the key to equal opportunities

**MARIUS LOTTER** was three days away from starting his first job when he became disabled in a diving accident.

That was 20 years ago and for much of the time since he has lived at Summerstrand Cheshire Home in Port Elizabeth, South Africa.

As the years have gone on, he has established a more independent lifestyle and he and two friends now reside at an independent living flat within the home.

Marius was keen to take this one step further and, with the aid of the computer in his room, began a book-keeping course.

His obvious talent for figures impressed then head of home Ken Jones, who asked him to buy all the food for the home.

He agreed – and the first year he kept the home's books, Summerstrand spent exactly the same amount

on food as it had the previous year – defying a 15 per cent increase in prices. Since then, he has been challenged to tackle the home's accounts.

"I did do the books of a civil engineering firm, from my room, for about four years," says Marius. "Unfortunately business became slack and they had to let me go."

Marius is just one example of how computers are demolishing the barriers – physical and discriminatory – that continue to obstruct disabled people in the working world.

There is a lot of work still to do and in many cases the barriers will seem immovable for some time to come. But with the aid of computers, disabled people all over the world are gradually beginning to be judged by employers on their competence to do a job – and nothing else.

Secretary Harriet Harman attended the national launch at Millbank in July and announced the project would receive £256,900 from the Government's New Deal scheme. Top UK companies have donated computers to get us on the road.

"I have been promised to be considered for a job by a national radio station after I've completed my course," says Penny. "They have been extremely supportive and very interested in what I am doing, but were adamant they could not consider me before I had done the course – and why should they?"

"At the end of the college course I'll be able to prove I know what I'm talking about. It will be satisfying to be judged on my application alone – not whether they have to move a couple of desks to get my wheelchair in."

A recognition of the part that disabled people can play in the working world is long overdue –

but Leonard Cheshire is working across the world to try to make the most of the opportunities that computers can offer. Among the applications for our International Self-Reliance Programme grants (see page 6) are many from centres who want to offer classes in computing to disabled people. As we move into the 21st century, almost every one of us has to learn about computers if we are to get on. We are having to learn to talk to each other through screens and pushing buttons. Not only can we talk to, perhaps do work for, people on the other side of the world – we also have no knowledge or preconceptions about the person at the other end of the line. No preconceptions means no discrimination.

It's a brave new world for all of us. And for the first time ever, with the help of Leonard Cheshire, disabled people are in on that revolution at the start.



# A mountainous challenge ...

66 people recently returned from a Himalayan adventure which shows just how far some people will go to raise money for Leonard Cheshire – more than £100,000, to be precise, which will be shared between a variety of Leonard Cheshire projects. Trekkers **JULIAN HOLMES-TAYLOR** and **LUCY HAMPTON** report.



**DAY 1:** We arrived at Heathrow Airport and could immediately recognise those people who were going on the trek. Not just because they had huge rucksacks, roll mats, sleeping bags and walking boots, but by the look of apprehension, verging on fear in some cases, on their faces! Having gathered the 66 trekkers (age range 18-71), given them their week's supply of t-shirts and checked them in, it was off to duty free and then the bar! By the time the plane finally took off the apprehension was already beginning to fade as people started voicing their fears and excitement of the adventures that lay ahead of us – or maybe that was because of the Dutch courage recently consumed!

**DAY 2:** After a six-hour flight we arrived in Tashkent at 8am local time and were greeted at immigration with some surprise, or maybe it was panic being confronted by 70 Westerners! Our Russian guides and a local brass band were there to meet us and we were then separated into two very warm coaches and began

our journey to Kaskasu Village in Kazakhstan. Four hours later we transferred into smaller local buses, which were soon named 'ovens on wheels'. The last part of the journey took us to the gorge of the River Saryaygir, where the trekking began! After a leisurely three-hour/seven-km walk we arrived at our ready-made camp where we were greeted with cups of hot green tea and cheery welcoming smiles from the Russian camp staff. Once we

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**'Within minutes the heavens opened and rain, sleet and then hail the size of golf balls descended upon us – oh, what joy!'**

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had all found a tent (and someone to share it with!) Mark and Karen (the Trek Leaders from Across the Divide), David (from The Big Event Company) and Steve (the Trek doctor) briefed us on the week ahead, the dos and don'ts – eg how to burn your loo paper after use, to let someone know when you are going and the importance of hygiene once you've been!

**DAY 3:** Wake up call 6am! After a breakfast of frankfurters, mashed potato and cold peas, (although a bizarre concoction, it tasted rather good!) Mark and Karen briefed everyone on the day's challenge. Once we had got into four groups the warm-ups began and then the first group set off. The first river crossing was imminent and consisted of a fallen log and two ropes. On first sighting it did seem ominous but all the guides seemed very experienced and we were all safely across in no time. We carried on through beautiful meadowland, and then began a steep ascent. At the summit a photo session took place and refreshing watermelon was served.

After a brief respite we continued on our journey. Moments later thunder could be heard. Within minutes the heavens opened and rain, sleet and then hail the size of golf balls descended upon us – oh what joy! After several cups of hot green tea we carried on with much vigour and gusto on our slippery descent to the valley of the River Sayrams. One more river crossing and we found our second campsite amidst a conifer forest. After a lot of rummaging around for the correct rucksack the scramble for the best tents commenced. Having put on dry, warm clothes, we were served a welcome meal of soup, stew and salami and then it was off to the campfire where music and merriment were the order of the night.

**DAY 4:** Today was definitely a challenge! 16km and eight hours of walking were ahead of us. The route would take us up to the lake of the river Sayrams. The ascent to our lunch stop was very steep and narrow but everyone eventually made it. A small group of us who felt fit enough attempted to reach the upper lake (2350m). Unfortunately after a





gruelling two-hour climb the lake was nowhere to be seen and as it was getting late we had to turn back. That evening there was more singing around the fire by Terry and Rebecca (two of the trekkers) and Sasha (a member of the Russian team). Entertainment was also provided by two other trekkers, one of which had mislaid a boot and ended up with an odd pair! This was luckily resolved by day break!

**DAY 5:** Today we moved camps again. We had a huge climb ahead of us and we had to gain 1000m to get there! The lunch stop was memorable, especially for Rodney (a Trustee). Having had his lunch Rodney decided he needed to get more water for the long climb ahead. Perched on a rock, Rodney lowered his bottle into the fast flowing river, lost his balance and toppled headfirst into the water. Hearing screams from members of group four, Ian, their guide, leapt into action and managed to pluck a shocked and shaken

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**'To celebrate our final day we were served Uzbekistan champagne and vodka. Unfortunately by the time the food arrived several people we in no fit state to appreciate it!'**

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Rodney from the river. Dry clothes were offered by other members of the group and after a brief check over by the doctor he was pronounced wet and well! Luckily he had only a small bump on his head; the bottle was never to be seen again.

After a steep six-hour walk we reached a large alpine meadow and nesting under the highest point of the Ugamsky Range, the Sayramkiy Peak, was our camp. The views of the snow capped mountains behind us and the meadows below were absolutely breathtaking, a truly stunning location.

After dinner and a very quick briefing (at 2750m the temperature dropped dramatically once the sun had gone in) Serge, a Russian guide, captured our attention recounting his recent adventures climbing Mount Everest.

**DAY 6:** For those feeling fit today there was a walk up to the Sayramkiy Glacier (3500m). The first ascent was quite abrupt, gaining 1000m over three quarters of an hour! We criss-crossed the stream that was flowing underneath the powder-white and, in some



parts, steely-grey glacier. The temperature had now dropped and was noticeable if we stopped for any length of time. The glacier itself resembled a white expanse nestling in a huge natural amphitheatre. We trekked on until we reached the centre of the glacier. After settling down and finding a rock to rest we spent a few moments in silence, listening to the stillness, the water flowing beneath the glacier and the cracking and melting underfoot.

A smaller group of six trekkers took a slightly easier route to reach the snow-capped mountains on the other side of the glacier and the rest of the group had a restful day at camp. That evening, around the campfire, the Russian cooks were introduced and thanked for all the amazing food that they kept producing.

**DAY 7:** It was reminiscent of a scene in MASH. At 8am a large ex-Russian army helicopter loomed into view with a noise that can only be either severe thunder or a large helicopter! The huge ship descended from the sky into the middle of the camp to collect our luggage, sending tents, hats and breakfast flying. After the group photo we set off for our final descent. Eight hours downhill! Having successfully reached flat ground, we walked through orchards and fields and were offered fresh honey straight from the hive from a local family who had never seen so many people walk through their field. The final stretch of the day's walking was slightly further than anticipated and we reached our final camp in darkness. This was to be our final night sleeping under the stars and to celebrate our final day the English guides provid-

ed Uzbekistan champagne and vodka and the Russians provided their local dish of Plov. Unfortunately by the time the Plov arrived, several people were in no fit state to appreciate it – a night that most of us couldn't really remember until later the following day!

**DAY 8:** This morning's breakfast was definitely not what was needed after the night before – three cold fried eggs! Our final hike was 5km along an easy track to the local buses that took us back to the village of Kaskasu (back into the 'ovens on wheels'). We waited here for the coaches to take us back across the border into Uzbekistan and Tashkent. Everyone seemed to be lost in their own thoughts, reflecting on their own achievements of the last few days and taking in the last views of the mountains that we had climbed. A feeling of achievement coupled with sadness filled the air.

There was an unexpected lunch stop an hour from the border – caused by a flat tyre – and we arrived at Tashkent a little later than anticipated. After a frantic shopping expedition we arrived at the hotel where at last we were to have a much-needed shower, shave and a look in the mirror. This was well worth the wait!

That night was the big farewell dinner. As people came down to dinner the transformation was amazing! Everyone looked so clean and fresh, it was hard to recognise some people! After dinner David thanked all the guides and Julian awarded prizes for several categories. Then the disco began!

**DAY 9:** There were several bleary eyes at breakfast, as sleep for some people had obviously not been their main priority the night before! After another breakfast of fried eggs (hot this time!) it was off to the airport and back to London. On the plane people exchanged addresses and began planning visits to one another. As the plane touched down at Heathrow reality set back in. Thoughts were in conflict, strong memories of what we had just experienced and reality of work and home ascending into our lives.

**■ SEE YOU NEXT YEAR? A Leonard Cheshire team is planning a second assault on the Himalayas in 1999 – and you could be there! For a completely different way to raise money for Leonard Cheshire, ring 0171 802 8241 for details. This year's trekkers say you will not regret it!**





# Personally speaking ...

Four disabled people from across the globe recall how much Leonard Cheshire services changed their lives

## **Theresa Cornell, LC Tobias House independent living apartments, Toronto, Canada**

**I AM the fourth oldest of five children in my family.**

I was born on Cape Breton Island, Nova Scotia with a physical disability called arthrogryposis, a condition which has forced me to be dependent on others to help me with my personal, domestic and professional needs through the course of my life.

I am now 36 years old and the single mother of a healthy 18-month-old baby girl.

In 1984, I decided to further my goals of living independently in the community. Nova Scotia funding was very limited in allowing people with physical disabilities to live on their own in the community.

During my stay at the Orthopaedic and Arthritic Hospital in Toronto, I began my search for independence. The applicant waiting lists were long and in Ontario the vacancies were limited in Support Service Living Units (SSLU) – units scattered throughout apartment buildings which are modified for individuals using electric and manual wheelchairs.

In late 1985, my persistence paid off. An SSLU had an opening in which they were having difficulty finding a tenant with a disability. With many long-distance phone calls and after cutting through much red tape, I secured the apartment and moved from Nova Scotia to

Toronto on March 24, 1986.

Eight years later, I decided to take another step forward. I left the SSLU and ventured out on my own with someone with whom I was prepared to start a family. But in 1997, my relationship and living arrangement changed and as a result, I was in desperate need of finding suitable housing, and appropriate support services for my daughter and myself.

After travelling a difficult and rocky road, I moved into Tobias-Carlton Street in February this year. Since moving in, I feel I have gained more independence that I could ever have gained from any other support service provider.

My daughter has adjusted very well to the transition. She is comfortable with the independent living assistants (ILAs) who are coming daily into my apartment, and with her caring day staff during the work week. I feel very safe, not only for myself, but also for my daughter. The support I receive is outstanding and the staff are always courteous, efficient and open-minded.

The ILAs do not make me feel I'm a burden when I ask for assistance. In the past I have felt like I was tied to a piece of furniture which never allowed me to move very far. My independence has been enhanced when I am out in the community with my daughter, as my ILA travels



■ Theresa and her daughter have settled in to their new lifestyle

with me for shopping and doctors' appointments. I no longer worry about the assistance I require when I am out of the apartment, which has been a burden for me for most of my life.

Tobias has given me not only a sense of freedom and independence, but also the right and freedom to raise my daughter with the full intention of teaching her the same values I had growing up.

# I have a job as a switchboard operator

**I come from Clonmel, Co Tiperrary and, at 42, am the oldest in my family, having five brothers and two sisters.**

I first came to St Patrick's 24 years ago in 1974. I have seen a lot of changes since I came to live here, all for the better.

I am now employed as the switchboard operator and I love my job very much. If I had the opportunity I would love to apply for the same job outside the Home, but it is not possible for me because there is no access for disabled people into most buildings.

## **Josephine Britton, St Patrick's CH, Tullow, Co Carlow, Ireland**

I did a lot of training for this job and it was well worth the effort. My ambitions for the future would be to get a job outside St Patrick's. I know three people who have the same job as me at Ardeen CH, Shillelagh.

I start my day at 8am with help from the night staff to get from my bed to my chair. After breakfast at about 9am I start work and finish at 5pm. I take my dinner break between 1pm and 2pm every day. If I need time off

during the week the manager, Shauna, will cover for me.

My hobbies are socialising and watching television and I love country music – maybe two or three times a month I go out to see bands playing.

I visit my family in Clonmel, where my parents still live, about once a month. I am very happy here at St Patrick's – there is always something for me to do or somewhere to go.





■ Nilda Zapanta now has her own store – a business which started with her selling cigarettes to passers-by under a mango tree

## We have our own business

Mrs Nilda Presidente Zapanta, Tahanang Walang Hagdanan, Ronilda Store, Marikina City, The Philippines

**WHEN I was born, my uncle said I was dead for a few minutes. God revived me and I am still alive – but my mother died after giving birth.**

And when I was only four years old, I became a polio victim. Then my father died, leaving me an orphan with my three elder sisters.

But my uncle adopted me and took good care of me, treating me like I was his own daughter. I never went to school. My uncle couldn't afford a wheelchair for me, so taught me at home instead of carrying me to school.

My three sisters were very busy. I didn't want to be a burden to them and in any case, perhaps they never expected that a disabled person and his or her capabilities would become more accepted by society. So I continued to teach myself in my own ways – I read books, magazines and any other material I could find.

Then tragedy – my uncle died of a heart attack.

I was placed under the care of my sisters and through my adolescence I felt my life was boring, useless, worth-

less and stagnant. I wanted to prove I could afford to live alone and be self-sufficient.

With the help of a penpal I sent a letter to Sister Valeriana Baerts, founder of Tahanang Walang Hagdanan Cheshire Home. I told her of my longing to be independent. I asked her to help me, to give me the opportunity to prove to people around me that I could stand alone.

Sister Valeriana put me in touch with the Home, where I was able to learn new skills. The training I received there enabled me to get a job in a garment factory in Quezon City as an embroidery designer. Then I met an able-bodied gentleman, Rudy, who helped me with everything I did.

I got my independence through Sr Valeriana and Tahanang Walang Hagdanan. I went on the electoral roll. I sent letters to newspapers about society in general and my views on the government and I'm very proud to say I was a part of the 1986 people power revolution against President Marcos.

The garment factory closed down and I lost my job, but I didn't give up. I bought some cigarettes to sell – I became a vendor under a mango tree. Rain or shine, every day I sat on the sidewalk to sell cigarettes.

My money grew, I got more confident and I got my own shop! Rudy, who was now my fiance, quit his job and helped me to manage the business.

And who would have thought that one day I would go down the aisle! Some of my relatives couldn't believe it when they saw me in my bridal dress, coming down the aisle and exchanging my vows with Rudy.

After many months and years of being diligent, we have a house and shop here in Marikina City.

I'll do my best to fulfill my duties as a wife and mother, doing the chores – preparing our meals, cleaning the house, washing clothes and feeding the pet dog!

In moments of reflection, I recall the past. Perhaps if I had met Sr Valeriana during my childhood, perhaps I would have been educated formally. But she is still always there today, ready to help at once if I need any support or advice.

But above all, I want to tell disabled people all over the world. You must believe in yourself and your ability more than anything else – if you don't, no-one else will.



■ Nilda Zapanta at home

## The Newcomer

Ruth Jerri Elliot, Cheshire House, Londonderry Northern Ireland

Alone, leaving all I'd known behind.

Everyone that meant anything at all to me is now gone, Even the love of my dog. The space in my house, the room to move around. The very fact that my house was my home. The familiar faces of the neighbours' kids popping in to say hello is all in the past. I even said goodbye to my Church.

How can I adjust? To this place I've to call home which is Leonard Cheshire. Is it as strange for the others as it is too for me? When at first I'm too shy to leave my room, or even to say hello to someone new to me. Afraid to join in in case I'm unwelcome. Afraid to venture too far. What will I do when tomorrow comes? When it hits me this is to be my fate, A stranger, What shall I do?

Is this or that right? Shall I complain or leave alone that dripping tap? Where can I put my things? There's not room to swing a cat. Dare I Go Out? But to Where? Who With? Is my life over? I'M DONE.

I cried So much at first, Is it so hard for everyone to settle in?

What's WRONG WITH ME?

Then as the days turn to weeks, an odd knock at the door, the Warden calls just to see you're all right. A meeting together, a night out to let our hair down. A new group, A new interest or hobby keeps me amused and busy for a while.

Times when I'm sick or afraid, it's nice to know I'm not Alone.

The place is bigger than it first seemed. There's still a lot to iron out, But it's a comfort to know that there is a Cheshire Smile.



# I'll stay in touch – office Christmas

**E**VERY time I came in to work, I knew part of my job would be talking to my friends all over the world. That's what really made my job special."

After 17 years as a lynchpin in the Leonard Cheshire International office in London, LCI secretary Lynette Learoyd retired this summer – and there are many parts of her work that she is already missing.

"The job was always so rewarding and so varied," she says. "The work of LCI holds your interest – I think that's why the turnover of staff in the department is very slow."

Lynette began her career with Leonard Cheshire just after we had moved into a new central office at Maunsel Street – as a temp, in 1981.

"I worked for an agency who told me I had some work with a charity which helped ex-servicemen!" she says.

"It didn't take me long to realise the true nature of the organisation's work! Leonard's book *The Hidden World* had just been published and there were other books around that I read and found fascinating."

Lynette's first job was helping then international director Ronald Travers to tie up the loose ends and final correspondence following an international week that had just taken place. A reorganisation meant a vacancy arose in the department and Lynette became a full-time member of staff.

"I began as a sort of PA to Ron, but the job sort of grew as Leonard Cheshire's work expanded. I'm not sure of the figures, but I wouldn't be surprised if there aren't more than double the number of international services than there were when I started," she says.

Such growth made the job an exciting one – and a varied one.

"There have been so many changes over the years. In some parts of Africa, for example, there is such a range of services. When I started we had a lot of Homes. We still do, but now we have mobile clinics, short-term rehabilitation, self-reliance, skills training, work that involves family and neighbours of disabled children and adults. There is much more of a community feel to many of our services these days, which enables us to support more people.

"And the variety is so great across the world – Leonard Cheshire services in Africa vary enormously and, because of the culture,



differ so much from those in America, or Asia, or Europe, or the Caribbean."

It was this individuality, says Lynette, that helped a lot of the international services going after the shock of Leonard Cheshire's death in 1992.

"He meant so much to so many people," she says. "Everybody knew him – not least because, when a service started, he would be instrumental in its planning and would make trips to the country to meet the people. He touched the lives of everybody with whom he came into contact – and that was a lot of people.

"He had been their friend, their contact and their adviser in London. After he died, Sir David Goodall [then LCI chairman, now UK chairman] decided LCI representatives should increase the number of visits they made, initially to help support services who

might feel a bit lost – as we all did – without Leonard around."

But Lynette thinks the founder's death helped the services to grow stronger.

"Every service had to become more dynamic, had to become stronger. Many of them have had for years – and still have – very strong people behind their local committees who have helped to support them locally.

"As a result they have developed more and more independently within their own cultures. But they remain Cheshire services and will always do so – they have that very strong feeling about them. They may be very different, they may represent different cultures but you sense the atmosphere of a Leonard Cheshire service the moment you enter it – no matter where you are in the world. I don't know what you call it –



# I took the card list ...

**LYNETTE LEAROYD** has retired after 17 years as a lynchpin of the LCI London office. The spontaneous standing ovation she received at the end of World Week showed just how much she will be missed by the hundreds of people she has helped from across the world. Lynette talks to *CSI* editor Peter Taylor-Whiffen about her job, the changes she's seen – and what exactly she'll do now ...

'Cheshire spirit', maybe – but it's definitely there."

Lynette's role as one of the points of contact for services has meant she has often been the first in London to hear how outside situations have affected life inside a service.

"There have been natural disasters, which have led to homes' roofs being blown off, that sort of thing, but one of the most frightening situations is, of course, war.

"During the conflict in Liberia, for example, it was impossible to make any sort of contact with the home for months. We had no idea on how people were – indeed, if the home was still standing.

"We often learn the details through the British Diplomatic Service and in the case of Liberia, their man actually stayed behind to see the children safely out of our home, which was in the middle of a war-zone, and into the care of a Medecin Sans Frontieres programme in Monrovia. Without such help in such situations LCI would find it so much more difficult to operate."

Lynette believes LCI is going from strength to strength. "The new regions that have been set up are an excellent way forward, particularly in Africa [which has been divided into three regions] because it's such a big continent. It's all a move towards LCI services continuing to be autonomous but, whereas they might have looked to London for guidance, they now have a region they can identify with, and which, being local, can identify with them. The training and development officers will also help to support them and while London will stay the centre of the worldwide LCI administration, it will be on hand to support decisions that are taken regionally and locally."

But what of Lynette? She bowed out at the end of World Week, when she received gifts and a rapturous standing ovation from delegates from all over the world, which

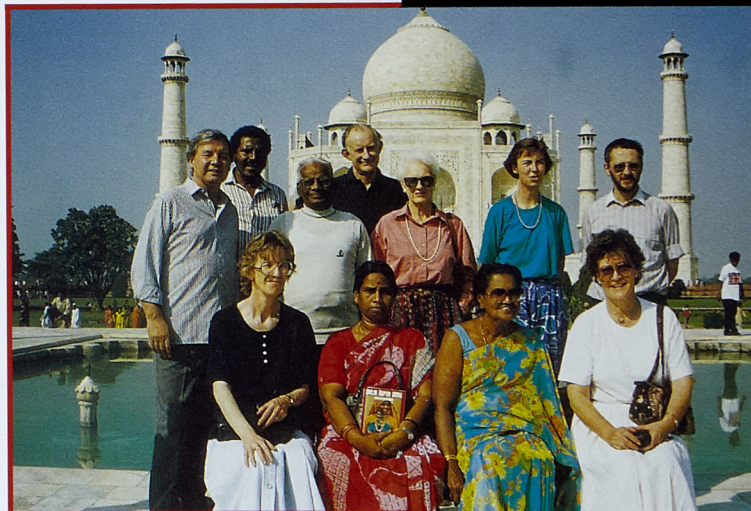
showed how much they will miss her presence in London.

"That was such a very moving moment," she says. "I am just very grateful to have been able to help them, and grateful for all the support and help they have given me. LCI has a very good team all over the world and in London, and I am sure it will go from strength to strength."

And what of the future? "I loved the idea of the international connections, so I am looking into the possibility of teaching English as a foreign language," she says.

"I've also taken up watercolours classes, and there's always gardening and decorating to be done.

"But I shall stay in touch. People all over the world have become my friends. You will be hearing from me – I've taken a copy of the Christmas card list out of the office!"





# WORLD WEEK 1998 WORLD WEEK 1998 WORLD WEEK

- It was the biggest-ever single gathering of people whose lives have been influenced by Leonard Cheshire.
- It drew disabled people, their carers, service staff and volunteers from more than 30 countries across the world.
- It attracted huge media coverage – and even an invitation from HRH The Prince of Wales to his London home.
- It was a chance to renew old acquaintances and make new friends. It was for many the experience – and the party! – of a lifetime.
- It was a chance for people to sit down together and make real, tangible plans about how we can improve our services and enable more and more disabled people to take more and more control over their lives.
- It was a fitting highlight of a year of celebrations to mark 50 years of extraordinary vision and achievement. It was ...

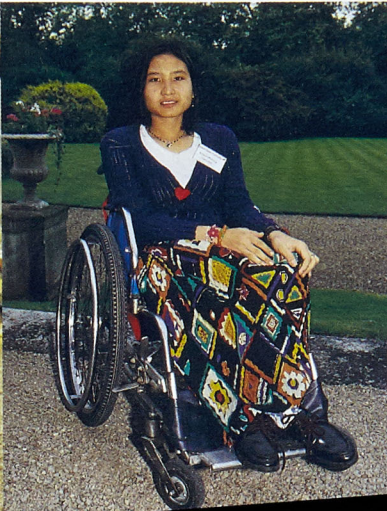


# WORLD WEEK





WEEK 1998 WORLD WEEK 1998 WORLD WEEK 1998



# WEEK 1998!





# A family of nations comes together

FOR many staff, volunteers and service-users, World Week was always going to be the highlight of a year of celebration.

More than 300 delegates from all over the world gathered in London to mark 50 years of Leonard Cheshire and to plot the way forward for Leonard Cheshire International – including how the UK and international homes can support each other now and in the future.

The key to the success of the conference was the involvement of service-

users. Their degree of involvement in the conference, of a greater level than at any previous LCI World Week, made this event a landmark occasion for Leonard Cheshire.

Service-users' substantial input into the planning, the presentations and the workshops shaped the themes of the week and the way forward that emerged for LCI and individual services as the week drew to a close.

The week-long conference heard experiences from service-users from all over the world, covering disabled

people's own experiences of empowerment and advocacy, self-reliance and the move from residential care to community support.

It also addressed the practicalities of the harsh realities of running a service, running service-providers' workshops on planning, funding, income-generation, publicity and marketing.

In this special diary of the conference, we recall the main issues and speeches and, most importantly of all, the crucial decisions that came out of World Week 1998.

**L** EONARD CHESHIRE International director Rupert Ridge sets the tone for the three days of discussions by telling delegates: "This is a time of great change."

He emphasises that while Cheshire Homes form the cornerstone of our history, there are few services in the world that are purely residential or offer only one type of provision.

"We strive to create the right environment for disabled people to determine their own futures," he tells the conference.

## day one

"Partnerships with disabled people are the key to our work, which means listening to the views of disabled people and involving them at every level of decision-making and activity."

Following this theme, Rupert sets goals for the week, expressing the hope that service providers are inspired and motivated to develop their services and that LCI has a clearer picture

of the way service-users see the development of their services.

"Societies across the world have, for generations, hidden disabled people away, either keeping them out of sight at home or sending them to institutions where they have lived segregated lives," he says.

"The reasons for disabled people being excluded are complex but the root causes can often be attributed to ignorance.

"As we approach the 21st century this situation is rapidly changing – an improved understanding of disability issues has forced a shift not only in attitude but in service provision," he says.

"This has led to the development of support services which are no longer based on exclusion and segregation of disabled people – rather, they are founded on the principles of empowerment and inclu-

sion. This World Week will focus on these changes."

**LCI Assistant Director (Training and Development) Joanne Martin picks up the theme as she tells the conference about the Leonard Cheshire International Training and Development Support Programme.**

The programme works with service users, families, staff and service providers to help them to identify and achieve their development goals and to adapt to the changing needs of disabled people.

Underpinning all of this is a team of regional training and development officers (TDOs). These people are based in the region and co-ordinate training on a regional level, which places the emphasis on local needs being addressed by local people, ensuring encouragement, practical and professional assistance to

"With a family such as ours, there are many bonds. We may deal with problems differently and we may face different situations but we do know that we belong to the same family and we value certain ideals above all others.

"At the top of these I would put the God-given dignity of the individual and his or her right to live a full life and to make the important choices of that life."

**Baroness Ryder of Warsaw**





develop their services in a way they feel to be appropriate.

"A regional office is much more accessible to services in that region," says Joanne.

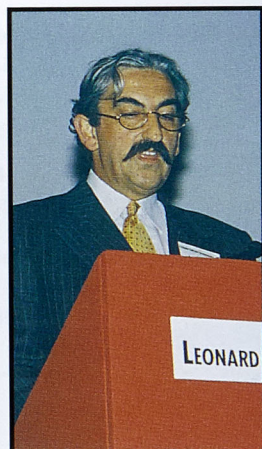
"A highly qualified and experienced TDO who is a regional national will bring not only the professional competence to the job but also an understanding of the culture, economics and politics of the region, all of which greatly influence the development of a programme.

"Finally, regional staff are better placed to listen, respond and offer support."

Joanne says the TDOs are backed up by a UK-based team of herself, Alice Bradley and Roy McConkey, who offer technical, professional and practical support to the regional programmes.

"The LCI team listens to individual services, service-users, staff, committee members, volunteers and our regional programmes," says Joanne.

"We believe that it is as a result of listening that we are able to offer the most appropriate support"



## The Opening Ceremony Kensington Town Hall

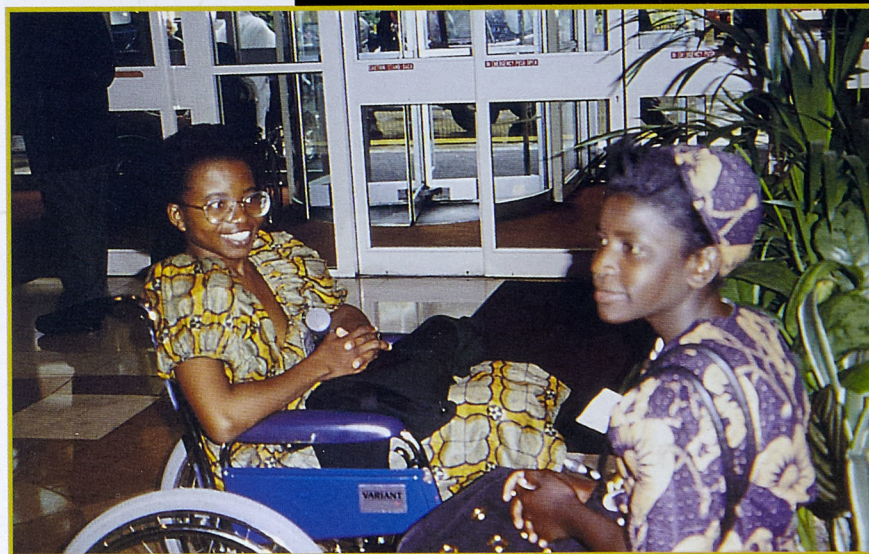
WORLD Week opened at Kensington Town Hall, where the Commonwealth Secretary-General Chief Emeka Anyaoku told delegates their activities were "rooted in a noble ideal.

"It is desirable that we should be sensitive to the merits of placing the emphasis not so much on disability as on ability," he said. "In this, Leonard Cheshire provides a notable example of best practice - you do all you can to enable people to do things."

INTERNATIONAL Training and Development Adviser Alice Bradley then explains the role of the regional teams which, she says, "work in equal partnership with all the Cheshire services in their region and with other local and national organisations working with disabled people".

Alice explains that the regional teams visit services and run training events, but also help services to make use of local and national training programmes run by other organisations. They also, she says, assist with fund raising,

*Contd overleaf*





# A partnership that involves everybody

advising services and providing information about likely sources of funding.

Southern African TDO Penny Mharapara takes the floor to give a personal perspective on her job, and tells the conference the major part of her role is "supporting Cheshire services to help them to reach their full potential" by developing means for appropriate staff training. "The aim of this is to enable staff to provide quality care and rehabilitation by sharing ideas and developing skills," she says.

**SISTER AGNES**, who is the head of the Limuru Cheshire Home in Kenya (featured in *CSI* January 1998), tells the conference of her experience of the training and development support programme.

"I have come to recognise the need to empow-

## day one

er residents," says Sister Agnes. "Before, I always felt it was the responsibility of the manager to take everything upon themselves. This meant things like meals and meal-times were arranged for the benefit of staff.

"As a result of a recent training workshop, we have been working with the residents. I realised that by involving residents more in the running of the home, I have created more time for the staff and management to concentrate on other activities."

Limuru resident Josephine Wanjiku helped this process by attending a training workshop in Zimbabwe.

"Since my return I have been able to organise three workshops with residents at Limuru," she tells delegates.

"Before the workshop I did not take any responsibility around the home. I thought it was the staff's job to run the home and I used to complain a lot if I was asked to do anything. Now I take my responsibilities seriously and meet other residents to plan our input into the running of the home."

MAJOR General KM Dhody tells delegates of the LCI training programme that he and his staff have conducted in India.

"When we talk of disability, physical disability is only a small segment," he says. "It is the other aspects of which we also need to take note – psychological, social, educational, vocational, against which differently-abled people have to struggle. These, we felt, must be addressed in our training programmes and to some extent we were able to do so."

KM tells of the "essential subjects" covered in workshops, including quality of life and holistic development, but says there were some other

advantages.

"These sessions provided an excellent opportunity for Cheshire homes to interact with each other throughout India at different levels – residents, staff members, trustees, committee members. We invited people from other social/community organisations and necessity established that we have to move on together, collaborating to provide the necessary support."

**JOANNE Martin** outlines the International Self-Reliance Programme.

"Over the next three years, the training and development programme intends to fully embrace the principles of empowerment and self-reliance," she says.

"At regional and international level it will work to influence decision-makers to develop policies and systems that are fully inclusive of disabled people. At local level it will encourage the development of innovative programmes that will empower disabled people."

(See page 6)

UK Director of Public Affairs, Jeremy Hughes, shows delegates a Leonard Cheshire film, made by a leading BBC producer, about International Self Reliance, which shows



For a full copy of all the regional reports, contact the LCI office at 30 Millbank, London SW1P 4QD



examples of how our projects have already helped disabled people to earn a living and become independent.

In introducing the film, which shows projects in Zimbabwe, Ethiopia, the Philippines and India, Jeremy tells delegates it is a "fundamental right of all people to participate fully in modern society – to enjoy its fruits and share its problems.

"With work comes not just the money to sustain yourself and your family, but also dignity and confidence," he says. "I know self-reliance will mean it is a different world for tomorrow's disabled adults. I hope you are inspired by the film and that it will help us to make that dream a reality."



**UK Director General Bryan Dutton concludes the day in the conference hall by outlining the changes that have happened to Leonard Cheshire services in the UK over the four years since the last World Week.**

He talks of the reorganisation of the regions, the move into new services and the development of existing ones, including supported housing, 'care at college' schemes for disabled students at university and the progression of our services for people with acquired brain injury.

Bryan also talks about the Workability scheme (see page 8), service-user involvement, the Enabled campaign (see page 5) and the ongoing need for efficiency to survive in an increasingly competitive world.

"One of the things I take from today is the commonality of language we are using. We are all using the same terms, the same aims that are binding us together as a family with common purposes."



## A Government Reception Lancaster House

**PAUL BOATENG MP, now Parliamentary Under-Secretary of State, spoke about the importance of social inclusion for disabled people when he met delegates from around the globe at the start of World Week.**

Mr Boateng, who was then Health Secretary, was hosting a reception at Lancaster House in London and spoke of the necessity for a society which enables disabled people and ensures there are no obstacles to opportunity and options, especially in employment and education. Mr Boateng, who earlier this year visited Leonard Cheshire services in Hackney, London, UK, was speaking as the government considers its position on the social inclusion of disabled people in the UK.





# Disabled people must lead the way

**L**CI COMMITTEE member, and director of the UK's Motivation charity, David Constantine outlines the theme of the day by talking about choice and opportunity.

"Leonard Cheshire's basic philosophy has changed slightly and subtly," he says. "Instead of offering choice and opportunity to people with disabilities, it now creates opportunities with disabled people – it's all about working together."

Dennis Cooray, from the Sir James and Lady Peiris Cheshire Home in Sri Lanka, tells of the Home's journey from residential care to independent living. "A solid bank of assistance has enabled us to give our residents the very best support and a better quality of life," he says.

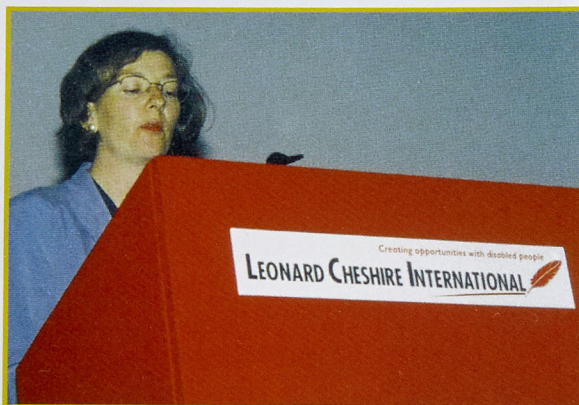
"Should we not offer the same quality of service to those in the community?"

Dennis is backed up by Puan Khatijah Sulieman, who tells how the Selangor Cheshire Home in Malaysia developed into a community-based rehabilitation programme "run by the families and the disabled community themselves, with support from all members of the public," and Susan Kambari, who outlines the nature of the Chihota community project in Zimbabwe.

"It is essential to include and involve disabled people, mothers of disabled children and local leaders," she says.

**"DISABLED people do not say 'ignore my disability' – they say 'recognise my dis-**

## day two



ability as part of who I am. Recognise it as part of what can help me to empower myself".

With these words Alice Bradley begins a session on empowerment and advocacy – and then hands over the stage for three disabled people to tell their own stories.

Alex Phiri from Zimbabwe, the conference learned, has been voicing his right to be heard ever since he was ten years old and "the doctors chopped off my legs".

He is currently secretary general of the Southern African Federation of the Disabled (SAFOD), which since its formation in 1986 has raised the profile of the needs and rights of disabled people, through campaigns on equal opportunities, employment and education.

"I would like to assure Leonard Cheshire that as SAFOD we are happy to be associated with you," he tells the conference. "There is a lot we can do together, especially in helping to raise the profile of people with disabilities in the management of your different functions and the delivery of services.

"The aims of Leonard Cheshire as enshrined in the charter look perfect – but writing is one thing implementing is a different issue altogether."

SHIVJEET Raghaw Singh sustained a spinal cord injury 18 years ago, which prompted him to study to become a psycho-social counsellor to people with such injuries.

He joined Delhi Cheshire Home in India in 1987 and is now working as a project

associate on Inspire, a research project which is building a programme of comprehensive rehabilitation for people with spinal cord injuries.

"People are frequently said to be disabled when they fall outside an accepted norm of behaviour," he says. "But the fact is one's ability consists of three main factors – physical, mental and intellectual. Intellectual and mental abilities are more important factors in deciding true ability."

**CLARE Evans heads the Disabled People's Forum in the UK and outlines the social model of disability, which she describes as a "liberating" concept.**

"Once people understand the idea that it's society's barriers and not us who are the problem, people talk about their lives being changed. The whole Forum is linked to disabled people's concept of independent living – not non-disabled people's concept of independent living; learning to tie your shoe-laces in two hours. What we want is the opportunity to have the assistance we need so we can spend those two hours doing what we want to do with our lives."

Claire also outlines her hopes for the advance of the role of disabled people within Leonard Cheshire.

"[We want] an organisation which is riddled with service-users' views, so it is



a natural thing for every piece of work that anyone does, to be informed with disabled people present – not just six disabled people who happen to be articulate, but hundreds of them.”

SISTER Delores Mwale is interviewed by Roy McConkey, whom she tells that it is essential to enable disabled children to be as self-reliant as possible.

Cheshire Homes Zambia (Sr Delores works at Solwezi) aim to integrate disabled children into mainstream school “which makes them equal members of society”. Solwezi staff recognise disabled children have often missed out on some areas of schooling and give extra lessons.

In a ‘round-table session’, Roy McConkey also interviews Melrose Cotay from Freetown Cheshire Home in Sierra Leone, which teaches its children skills enabling them to work with their families when they return home.

Sagai Mary, a wheelchair-user from Bangalore Cheshire Home, has a degree in engineering and a job with a large aviation firm. She tells Roy: “Being economically independent brings confidence and dignity. I am respected and seen first not as a disabled person but as a professional engineer.”

Another wheelchair-user, Richard Nzundamo, is chairman of the Katima Lulilo Cheshire Home in Namibia and tells delegates of the necessity of working to raise the level of respect people have for you – and improves your chances of getting married.

“A person who has a job is respected whether they are disabled or able-bodied and once they have that respect, they are able to overcome some of the negative attitudes that exist towards disability.”



## A Royal Reception St James's Palace

**MORE THAN 500** people celebrated the Golden Jubilee in the splendour of St James's Palace – in the company of HRH The Prince of Wales, our Golden Jubilee Patron.

Service-users from the southern half of the UK joined World Week delegates from all over the world at the event, which was held in the state apartments at the Prince's official London home.

Particular thanks goes to Shell International Ltd, who sponsored the event, and to Captain Jones and the No. 7 Company Coldstream Guards, who alleviated the waiting time for the lift by assisting those who were happy to be carried up the Palace stairs.





# Having a say – and taking control

**M**any residents do not feel they are afforded an acceptable level of personal dignity, many say they lack privacy and personal freedom, while there are few opportunities for people to have their voices heard.

These are the main concerns that come to light as service-users hold their own private forum away from the main conference hall.

The session, facilitated by Agnes Chishawa, Shivjeet Raghaw Singh and Alex Phiri, asked participants to consider the statement: "Leonard Cheshire International aims to be a responsive organisation which listens to disabled people and acts on what they say."

The session attracts positive and negative comments.

## day two

Most people are satisfied with some aspects of their service but dissatisfied with others. A few say they have no problems at all.

However, concerns common to many service users include:

■ **Personal dignity and support** – this is expressed as a major concern for many participants and includes being told when to go to the toilet and when visitors are allowed, not receiving personal care and support when it is needed and not having access to medical care and facilities when necessary.

■ **Lack of privacy** – this includes having nowhere private to spend time with relatives and a lack of privacy when dressing and going to the toilet.

■ **Lack of personal freedom** – for example, not being allowed to go out, being told when to go to bed and not being permitted to socialise.

■ **Failure of service users to have their voices heard** – some have no opportunities to give their opinions, have no communication with committee members and no power to make decisions or

influence in the running of the service, and having problems ignored.

■ **Staff** – some service-users are afraid of staff, and/or receive no attention from them.

■ **Getting out** – some service-users cannot get out because of a lack of transport or staff.

■ **Shortage of equipment and facilities** – some service-users complain of poorly-maintained wheelchairs and lack of equipment, facilities – and medical attention.

**A number of service-users say they want their views kept confidential, as they are worried about what will happen to them if they complain.**

During the session, service-users are also asked to com-





plete a questionnaire which asks them to comment on how Cheshire services are doing and how those services can improve.

The questionnaire throws up the following findings:

■ 46 per cent of service-users say their service does not have a service-users' committee where people can express their views – yet 93 per cent feel it is important to have one.

■ Just under half of services represented say service-users do not sit on themanagement committee – but 97 per cent say this is important and necessary.

■ 42 per cent of service-users present do not feel that in their service, users have opportunities for choice – eg when to get up and when to go to bed, etc. Everybody feels this is important.

■ 58 per cent of those present say users of their service are not involved in any decision-making concerning the running of their service.

■ 80 per cent say there is no opportunity to be involved in the appointment of staff – yet 100 per cent think it is important.

■ 37 per cent say they do not receive help and support they need to make friends outside the service – yet 90 per cent say this is important.

■ Almost half say residents in their Cheshire home cannot get the support they need to do things outside the home – but 96 per cent feel this is important.

■ More than half (56 per cent) say that in their service there is nowhere private where they can spend time with people close to them – yet 95 per cent feel this to be important.

A summary of the session is fed back to main conference for reaction the following day.



## HM Queen gives Royal approval Botanic Gardens, Edinburgh

HM The Queen and HRH The Duke of Edinburgh gave our Golden Jubilee celebrations the Royal approval when they attended a reception at the Botanic Gardens in Edinburgh.

The Royal guests met people who use our services in the northern half of the UK.

The event was organised by volunteer Sheila Gibb and included a special moment for Mary Jones, who lives at Glamis CH, Scotland, and who presented Her Majesty with a framed copy of specially-written pipe music.



# Do we live up to our Charter?

**H**OW well are we living up to our Leonard Cheshire charter?

It's quite a challenge for delegates on the final morning but the outcomes of the session, together with the views expressed in the last couple of days, will shape the final session of the week when the LCI London office and the services from around the world will decide the practical action they must take to maintain and improve our provision of support to disabled people.

Delegates are split into six

## day three

groups, each of which includes service-users, staff, committee members, trustees and other volunteers, as well as people from other organisations who have made presentations earlier in the week.

Each group discusses one of the five points of the charter, thinking about what it means in practice and what Cheshire services must do if they are to live up to

it. The session proves to be one of the liveliest and most thought-provoking of the week. While there are many areas in which service-users, staff and volunteers feel their service is doing an excellent job, there are areas in which it is felt the Charter's ideals could be better achieved, not least in terms of service-user participation, respect for disabled people's opinions and the

raising of disability awareness among the general public. However, the groups work together and work hard to identify the causes of problems, which enables them to proffer solutions.

The groups then come together for a final brainstorming session to discuss the support that is needed from everybody if LCI and its services are to achieve the required changes:

**THE support services say they require from Leonard Cheshire International includes:**

- Finance, equipment and information;
- Training for all – service-users, staff, committees, families and volunteers;
- Encouragement and information;
- Raising the level of world awareness;
- More start-up finance;
- Better quality control and advice from the UK;
- The need to establish 'think-tanks'.

SUPPORT required by services from their own regions includes:

- Co-ordination of activities among services;
- Regional fundraising;
- Regional service-user forums;
- Staff and resident exchanges;
- Guidance on laws;
- Liaison with government bodies;
- Training and shared learn-





ing through networking;

- Sharing of equipment and resources, both material and human, between regions;
- Better networking;
- Shared learning;
- Two-way information;
- Creating awareness through national and international education systems;
- Involving service-users in decision-making and on committees.

**THE conference also decides it requires support from other people and organisations:**

- Volunteer recruitment;
- Financial help;
- Advocacy;
- Adoption/sponsorship of users;
- Sharing of resources;
- Training and expertise;
- Government organisation of sale outlets for products made and quota systems in the workforce.

Finally, the delegates list ways in which they can help themselves:

- Maintain awareness and hope;
- Raise money;
- Strengthen the connection with the community;
- Recognise the importance of planning at all levels;
- Better communication;
- Mentoring and peer support.

## The service-providers' perspective

WHILE service-users are discussing their views about their service-provision, there is a parallel session for service providers.

Trustee and UK Public Affairs Committee chairman **Charles Morland** chairs the session, which focuses on planning and strategic development.

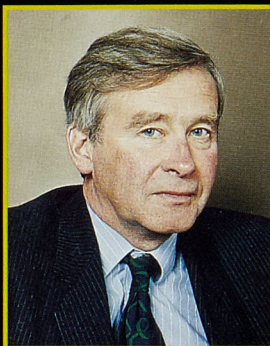
"Planning is essential to the development of service," he says, "and well-planned services are better fundraisers."

■ **Mrs Sekgabo Ramsay** tells the conference about the organisation behind the Leonard Cheshire services in Botswana.

"The strength of the executive committee has always been very important," she says. Sekgabo tells the delegates of fundraising initiatives including sponsored walks, where "invited walkers are usually business executives ... capable of securing large sums of pledged money" and a circus, which is brought from South Africa every year.

"It is labour intensive and takes four months to organise – but last year's profit was P140,000 pula."

■ **NKOKONJERU** Providence Cheshire Home in Uganda was to have closed down in May 1997 – until **Sister Jane Frances Nakafeero** was asked to



help.

"The home already had land, structures and local managerial capacity," she tells delegates. "What were lacking were some of the materials and the capital."

Sister Jane decided to restore three projects which had worked but now lay dormant – poultry, bakery and fish farming projects.

To revive the poultry farm, LCI gave a grant of £3,900 for 460 chicks and materials – and after much hard work, the home has been awarded the Sheraton Kampala Hotel dressed chicken contract and provides the hotel with 300-400 birds every week.

"The residents feel they are involved and appreciated," says Sr Jane, "and their improved diet of eggs, bread and chicken makes them happier still!"

■ **ETHIOPIAN** director **Negussie Wolde Sellassie** gives a presentation on making effective applications to local funding agencies.

"Project preparation is the planning of activities to accomplish a certain task towards achieving a certain goal," says Negussie. "It is always important to remember the four main stages – need identification, project formulation, implementation and evaluation."

■ LCI deputy director **Mark**

**O'Kelly** addresses the delegates on international grants, and urges services to keep him informed of applications made to various international funding agencies.

He urges services who require LCI's help in applying for funds from an agency to make sure they know why they want the money, what long term benefits the money would bring and how many service-users would benefit from it.

"Treat a donor as a partner," says Mark. "Say thank you. Invite them to see how their money is being spent."

"You never know when you might next need their support."

■ **THERE** are four audiences we should be promoting ourselves to, says UK Public Affairs Director **Jeremy Hughes** – disabled people, opinion-formers, staff and potential staff, and "the people who might give us money".

He also talks of the importance of competing. "We are a not-for-profit organisation but we have to compete with other people who are also trying to get attention, publicity – and trying to raise money."

■ **GOOD** and bad press are covered by **Brighton Ncube**, who tells delegates how to deal with the media by giving them what they want – but also warning of how to avoid the pitfalls.

"The media, when used well, can be a vital tool in developing services and, equally so, can do harm if certain precautions are not taken," he says.

"There is a need for organisations such as ours to maintain the interest of the media in our work."





# Making the vision a reality

**L**CI director Rupert Ridge sums up on the final afternoon and gives assurances that the issues discussed over the last few days will be addressed, the momentum maintained and resolutions upheld by actions.

"The energy of all the groups was an inspiration and a rekindling for all delegates returning to their services," he says.

"The importance to LCI is the raising of issues on which we can concentrate in the improvement of our performance."

There's a feeling of excitement as delegates come together in the conference hall for the last time. It's a feeling of excitement brought on by a feeling of achievement.

"Many old friendships were strengthened, many new ones made," says Rupert. "There were good social occasions, some formal, some informal.

"But this was primarily a working conference and in that it has achieved a great deal."

**LCI chairman Sir Patrick Walker sums up his view of the main features of the conference:**

"Firstly, it is the degree to which all the delegates were involved," he says. "The way in which problems were identified and solutions considered was immensely encouraging.

"It is clear Cheshire services throughout the world are adapting to changes in

## day three



the world itself and to changing attitudes to disability. There is still some way to go but the Cheshire family has begun the journey."

He also talks of "the immense value of hearing the views and experiences of members of the Cheshire family from around the world.

"There is no doubt that shared problems and the possibility of shared solutions are a great encouragement to all."

SERVICE-USERS have been in control at this conference. People have enjoyed the trips, the sight-seeing, the brush with royalty – the general party atmosphere.

But much more than that, for the first time at a World Week gathering there has been the opportunity for service-users to say what they really think about Leonard

Cheshire services and how they can be improved.

There has been the opportunity for service-providers to learn from each other and to tell the LCI what they really want from it and there has been the opportunity for LCI staff to listen to the concerns and issues that both services and service-users feel are important, to gauge how they can best carry forward the vision of Leonard Cheshire.

**SIR DAVID GOODALL, UK chairman and former LCI chairman closes the conference with an address about the spirit of Leonard Cheshire.**

"I suppose if you want to know what someone's spirit is, you should look at what they created," he tells the delegates.

"There is a real sense in which we ourselves are the expression of Leonard's spirit.

"When we talk about partnership we mean that we are all in it together. This equal partnership was certainly central to the way Leonard saw things."

He speaks of Leonard Cheshire's key qualities as being "empathy ... a respect for the unique human dignity of each individual person and a blend of modesty, humour and great kindness.

"When we come to codify our ethos and practice into a charter or a code of conduct, we must not forget that if everything we do is not infused with kindness, it is really not worth very much."

Concluding his address and the conference, Sir David recalls a message he wrote to services just after Leonard Cheshire died:

"What has made [Leonard Cheshire] different from other charitable organisations has been the founder's own personality.

"We share a responsibility to him and to his memory to carry on the work he began, in his spirit, in co-operation with one another and as fellow members of his worldwide family.

"I hope the experience of this World Week has given us all a deeper understanding of that responsibility and strengthened our determination to carry it out."



## And finally ...

"I would like to thank everyone who made the week the success it was," writes LCI director Rupert Ridge.

"I would like to give thanks to all those who spoke whether from the platform or the floor, who contributed to the high standard of debate and who without hesitation spoke honestly and strongly; always with the realisation of our founder's vision at heart – and to those within the Cheshire family and without who made it happen."

**WORLD WEEK 1998** simply would not have happened without the enthusiasm, support and hard work of many, many people.

Thanks to:

- Everyone who planned programmes or took part in presentations.
- Everyone who helped with organisation and transport, to both the conference hall and the social events.
- World Week co-ordinator Katy Evans.
- LCI staff Lynette Learoyd, Helen Ashenden, Jo Cospsey and Clare West.
- The Cophorne Tara Hotel
- De Beers
- Shell International Ltd.

Thanks finally to the 285 delegates who came from 42 countries – without whom none of this would have happened.

**FOR** a copy of the Leonard Cheshire International World Week 1998 Report, which includes full texts of all the speeches and the regional reports, contact Leonard Cheshire International at 30 Millbank, London, SW1P 4QD, United Kingdom.



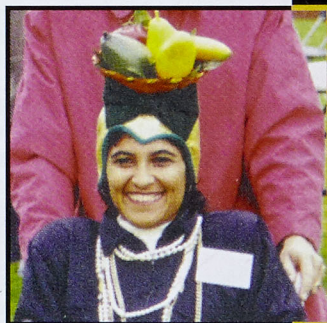
## A Golden Jubilee Day Le Court Cheshire Home

A DOWNPOUR failed to dampen the spirits as 600 guests attended a special Golden Jubilee Day at the first ever Cheshire Home, Le Court, at the climax of the World Week celebrations.

Leonard Cheshire's daughter Gigi and Lord Lieutenant of Hampshire Mary Fagan were the guests of honour at an event which for many people, particularly the international World Week delegates, was the culmination of a pilgrimage to the place where our work started 50 years ago.

Guests enjoyed the opportunity to look around the first-ever Cheshire Home and were entertained by the Band of the Brigade of Gurkhas and the Rose and Thistle Scottish Pipe Band.

"It was a wonderful day," said Le Court's Jenny Croucher. "The weather was dreadful and we had to cancel some of the events, but somehow the rain just added to it – it just turned into one giant party!"





## WRITE TO REPLY

IF you have any news or views YOU would like to share, please send them to:

Write to reply, Cheshire Smile International,  
30 Millbank, London SW1P 4QD, ENGLAND  
OR FAX on (0044) 0171 802 8250.

e-mail: J. Riley@london.leonard-cheshire.org.uk

# Let's continue to enhance living standards worldwide

## The holistic future

I AM writing in reply to Paul Gangi, who describes the feelings of frustration and isolation experienced by people with learning disabilities (CSI, July 98). Paul is evidently a thoughtful person.

I am able-bodied but have many disabled friends, some with learning disabilities. I have been impressed during the last 20 years by the spiritual qualities shown by disabled people – some have innate spiritual qualities, others have grown spiritually during their time of residence in a Cheshire home.

Spiritual qualities and values have always been held in high regard, but centre-stage has been taken in modern times by the achievements and prowess of the world of science. We are greatly indebted to this but it is beginning to be seen within the context of a comprehensive, holistic world view.

Progress can be made in many ways but nothing is more important than the element of experience and it is here that

disabled people have a special contribution to make.

I am currently engaged on a small piece of research concerned with the development of holistic approaches in the scientific and other aspects of contemporary culture. It occurs to me that Paul Gangi and others may be able to make an important contribution in cultural development arising from their experience of life.

It will first be necessary for their learning and other disability needs to be addressed and the support of interested friends and helpers will be required. A further possibility might be the setting up of a 'Leonard Cheshire Centre for Holistic Studies', with the object of encouraging discussion and communication with the wider cultural community. Perhaps New York or London might be a suitable location for the centre?

THANKS for giving me such a great opportunity to present my views and appreciations of Leonard Cheshire and its work with disabled people.

People with physical disabilities are all talented and their minds are full of things which can be of benefit to all of us. Begging is not the only occupation from which disabled persons can earn a living. They can do so many things and are doing so in Leonard Cheshire projects across the world – carpentry, typing, tailoring to mention just a few.

However, it looks as if disabled people are left behind owing to a

lack of finance. I would like to take this opportunity to appeal to the general public worldwide to give a helping hand to Leonard Cheshire, to give donations enabling it to enhance and improve the living standard of disabled people through its many educative programmes.

And to the workers of the various projects worldwide, they should talk to their residents and treat them in a way that they will feel in touch with them. With your help, all things are possible.

## Park House is saved

I WAS moved and heartened to learn that the Princess Diana Memorial Fund has awarded £1 million to ensure the future of Park House Hotel, Sandringham.

I have spent many, many happy days there and was very concerned to hear about the financial difficulties threatening its future. I want to say this news has cheered me up immensely as I am

hoping to spend many more holidays in the delightful environment of Park House.

I have always found the service to be of the highest standard and the range of activities available second to none.

It is comforting to know it has a secure future.

## So many people made it a week to remember

MUCH has been written and said about the Golden Jubilee's World Week and to this I would like to add my own personal thanks to the many people who made it the enormous success that it was.

I hope I will be forgiven if I spare myself the impossible task of singling out individuals to thank. There were so many people who, whether they were able to attend or not, made, in different ways, so many contributions to the event in its planning, preparation, execution and enjoyment.

Held six years after our

by  
**RUPERT RIDGE**  
Director  
Leonard Cheshire International



Founder's death, World Week demonstrated again the strength of the spirit of Leonard Cheshire. People from all over the world brought that message with them to London and shared it.

The result was a great embold-

ening of our common purpose – not only emotionally, but in practical terms too, for it was a working conference.

Great strides were made in sharing our experiences and in planning the future in community support, empowerment, advocacy, self-reliance, development and the network in which we can work together.

A meeting of regional chairman or their representative confirmed the importance of taking the work of World Week forward to the regions and their meetings.



# Worship is a common theme for celebration

THOUSANDS of people have celebrated the life and work of Leonard Cheshire by attending special Golden Jubilee thanksgiving services. Amid all the parties, simple, personal acts of contemplation and prayers of thanksgiving have been a common theme across the 50 countries in which Leonard Cheshire operates. Many homes across the world have used the Golden Jubilee as an opportunity to hold services either at their local places of worship or at their own premises. Large, public, communal events have also served to draw the extraordinary achievements of Leonard Cheshire to the general public.

In the UK alone, hundreds of people attended services in London, Edinburgh, Liverpool, Cardiff and Belfast.

More than 2,000 people

attended a service at St Paul's Cathedral, London, the scene of many previous grand occasions, to hear His Eminence The Cardinal Archbishop of Westminster Basil Hume talk about the contribution that disabled people had to make.

"Every person with a disability, whether of mind or body, has a gift that I am not, is something I am not," he told the congregation.

"Disabled people often have their own contribution to make to the welfare of others. They have resources and talents which must be recognised, developed and used, whenever this is possible."

In Edinburgh, Scotland, as in many other places, service-users themselves led the worship by doing the readings and playing the music.



■ **PAYING TRIBUTE** – 2,400 people hear Cardinal Basil Hume at the thanksgiving service at St Paul's Cathedral, London (above, below and bottom)



■ **Glamis House CH resident Dorothy Wollage teams up with John McIver and Robert Johnstone from LC Inverness to provide the music at the service at St Giles Cathedral, Edinburgh.**

