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**By Florence Garabedian**

**Lothian Centre for Inclusive Living**

LCIL BRIEF HISTORY





**Lothian Centre for Inclusive Living**

# A short, and incomplete, historical narrative of our organisation

## Foreword

As it says on the tin, this is not a proper history of LCiL, not even a short chronological factual narrative around the life of a unique organisation, influenced by a wide range of factors, over 30 years.

Due to time constraints, I have used only a very limited amount of historical material, comprising sections of a book I co-wrote with others about the life of Board Member Suselle Boffey, annual reports when available and audited accounts, and my own experience in leading the organisation.

The latter made it trickier to remain objective and to objectively select information for inclusion, in an extremely condensed narrative. As a result, people involved in this ‘history’ may well object to the prominence of certain events or developments, or be frustrated (but I hope not too angry!) by the absence of what they consider to be very important aspects of life of our organisation.

In striving to provide some wider context to this chronological report, I am very conscious that much information that would enable readers to fully grasp the beginning and end of particular developments, situations, projects, ideas, etc., is missing.

Nevertheless, I hope that by offering a coherent, even if imperfect, picture of the first CIL in Scotland until today, interested people will want to know more about it and about the Independent Living Movement, as well as the conditions within which - in the past, but most importantly today - disabled people are able, or not, to live their lives.

Finally, I would be honoured if my efforts here triggered a professional historian, or a student, to attempt to produce a better and more comprehensive historical account of our organisation.

* Florence Garabedian

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# Chapter One

## The wider historical context

It is often thought that the Independent Living Movement, which is the ‘cradle’ within which Centres for Independent Living were born, started in Berkley, California in the late 1970s, thanks to a group of disabled students who decided they wanted to be in control of their care rather than live in institutions and who, led by Ed Roberts, set up the first Centre for Independent Living.

It is important, however, to know that in the late 1960s, for example, the largest mass organisation of disabled people in the world already existed, in the UK, under the name of Disabled Income Group (DIG). It campaigned for the right of Disabled People to receive a National Disability Income.

At the time, many disabled people wanted DIG to represent their interests in a wide range of social issues faced by disabled people. As Vic Finkelstein, an active disabled leader of the time, said in his 2001 speech at Leeds University, *‘How to change an oppressive system rather than spend fruitless time appealing to the prejudiced to cease their discrimination?’*

On 20th September 1972, Paul Hunt (a disabled activist who had been living in residential institutions) wrote to the Guardian newspaper and the disability press calling for disabled people and their supporters who shared this view to joining him in forming a new organisation.

“*Sir, severely physically handicapped people find themselves isolated in unsuitable institutions where their views are ignored and they are subject to authoritarian and often cruel regimes. I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of the successors to the Workhouse.*

*Yours faithfully, Paul Hunt."*

The Union of the Physically Impaired against Segregation (UPIAS) was born out of the following exchanges under the leadership of Vic Finkelstein.

Initially, to remain true to its grassroots, under the influence of Vic Finkelstein who had lived under, and fought, the Apartheid regime in South Africa, the membership was only opened to disabled people. Most importantly, disability income was not seen as *‘compensation for disabled people’s personal defects. The issue was about oppression, not compensation. […] We don’t want to be compensated for being oppressed! We want people to stop oppressing us!’* V. Finkelstein. 2001.

Continuing, Vic Finkelstein also explains, ‘*So, to summarise [...] UPIAS decided that as there were already a lot of organisations that had been looking for compensatory approaches to the difficulties that we faced we had a choice: you see disability fundamentally as a personal tragedy or you see it as a form of social oppression. The times demanded that we had to put it as a clear choice between contrasts. If the central concern is ‘oppression’ then action for change needs to be ‘emancipatory’, civil rights, and so on. If the central concern is that we suffer from a ‘personal tragedy’ then action for change needs to focus on the provision of ‘care’ and ‘compensatory’ sources of income and so on. I think you can fiddle with these basic differences as much as you like but they are always ready to emerge into the open because this is the reality of the society in which we live.’* A personal journey into disability politics. Vic Finkelstein (Leeds University Centre for Disability Studies) 7th February 2001.

These views, however, were, at the time, very much seen as ‘revolutionary’, and disabled people with such an understanding of their own disablement process were seen as extremists. It was as if too many people were unable to conceive of another way to think about disability.

Promoting a radical theory of the interpretation of disability became necessary. This also challenged the disabled people’s community itself, along with requiring a different approach to the involvement of disabled people and the resulting effectiveness, or ability, to influence decision-makers. By then another organisation had emerged, The Disability Alliance, including ‘professional experts’ and academics.

In 1975/76 UPIAS produced the ‘Fundamental Principles of Disability,’ articulating the shared understanding of what disability is, with the Disability Alliance.

‘*Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.’* UPIAS (1976) The Union of the Physically Impaired against Segregation and The Disability Alliance discuss Fundamental Principles of Disability.

In addition to this, Mike Oliver, a disabled sociologist by profession, conceptualised UPIAS views in distinguishing between impairment and disability through the Social Model of Disability, which fundamentally does not place disability within people’s individual medical conditions but within the attitude and structures of society. By identifying as a disabled person, rather than a person with a disability, an individual was affirming that he/she was not so much disabled by her long-term condition, impairment, or ‘disability but by the barriers he/she met and which could indeed disadvantage greatly.

For many disabled people within the Independent Living Movement, the disabling process was not so much due to the physical or cognitive limitations experienced by a person but to the barriers – physical, social, attitudinal, economic – the person meets through lack of support, lack of access to many things non-disabled people take for granted, institutionalisation, and by the way disabled people are represented culturally and in the media. Once adopted as a tool to grasp disability, the Social Model of Disability fundamentally changes the perception one has of society about disabled people.

Supporting disabled people, or even caring for them (a concept many people within the Independent Living Movement are not comfortable with) is no longer about looking after, curing, fixing disabled people, or even normalising their lives, it is about addressing the societal barriers that discriminate and undermine their human rights.

The first Centre for Independent Living in the UK was set up in 1981 in Hampshire by a group of disabled people who had been living in a residential home. It was based on the same model of Independent Living Centres as those in the US. The local authority agreed to give them money to employ their own personal assistants. The first CILs developed the Principles for Independent Living which were based on 7 basic needs: housing, personal assistance, mobility/transport, access, peer counselling, information, and equipment.

**The Scottish Scene**

In Scotland, Edinburgh in particular, in the 1980s, the City saw an increasing number of disabled people aware of and influenced by, these other disabled people in the US and south of the border who aspired to live more independent lives, in control of their support and with the same choice and opportunities as non-disabled people. Involved in different and sometimes overlapping networks, groups of disabled people came together to initiate ‘user-led projects, organisations, events, and new networks. In Edinburgh first, then in Glasgow, over the years the Movement spread all over Scotland.

In the late 1980s one of these original groups, made up of very active disabled people who were self-organisers, excellent connectors, and all committed to the user-led model, was the Lothian Coalition of Disabled People (LCDP). One of its founders, Dougie Herd, wrote in Issue 28 of the ‘Lothian People’ that the aim of the Coalition was to:

*‘- create a democratic organisation of disabled people in the Lothians*

*- involve disabled people in the planning, organisation, and delivery of services*

*- support disabled people’s assertiveness, self-confidence, and empowerment*

*- secure by any peaceful means necessary equality of opportunities for disabled people.’*

Constituted in 1989, LCDP shared offices with other organisations, such as the Edinburgh District Council Women’s Unit Office, the Equality Council at Edinburgh District Council in an office in Shandwick Place - before the official inauguration in June 1990 of the recently refurbished offices at 13 Johnston Terrace, by Alistair Darling QC, MP for Edinburgh Central. On this occasion, Bill Fisher, Coalition Convenor, made clear that through the now established Coalition the voice of disabled people: *“would be heard more strongly. Providers of services, decision-makers, politicians, and the community at large would no longer be able to say that they didn’t know where to go to hear what disabled people had to say.”*  This could take the form of ‘IDEAL Training’, a consultancy service providing Disability Equality Training (DET) to organisations seeking to fashion their services to the needs of disabled people. It could also be through the ‘Women’s Group’ of the Coalition bringing out the collective creativity and vision of a group of strong disabled women. Keen to use photography to create different images of disabled women, ‘Snap Happy’ invited all women members, under the instruction of a tutor, to “take a lot of photographs of anything and everything and to attend a couple of portrait sessions.” As Suselle Boffey (a future member of the Board of LCiL) explained, in ‘Lothian People’, the LCDP magazine, *“then we were ready to think again about how we represent ourselves positively. Agreeing that we are not taking pretty pictures, or smiling faces, we began to sense that we need to be seen actively rather than passively.”* This initiative was one of many carried forward by many groups within the Coalition that characterises the energy, creative force and commitment of the time.

Although not all members of LCDP were employers of personal assistants or indeed needed social care support, the coalition had its roots within the Independent Living Movement. The movement’s members were clear that a means of living more independent lives and having maximum flexibility of support was to have a choice of who supported them and control over how this support was provided.

# Chapter Two - 1990-2000

## User-led and committed to peer support

A summary of the origins of LCiL, written in the 2000-01 LCiL Annual Report, on the occasion of its 10th Anniversary, explains how three disabled people living in the Thistle Foundation in Edinburgh (Shand Siverwright, Archie Ramsay, and Diana Roy) moved this forward. They had learned of what was happening in England and were convinced that employing your staff was the best way to ensure flexibility and control over your care/support, even if it brings with it responsibilities and is not for everyone. *‘They negotiated with the then Lothian Regional Council to set up what was, in effect, a direct payments system. Through word of mouth, more disabled people wished to join these pioneers and so the Lothian Independent Living Group (LILG) was born. After much work, financial negotiations, and with support from the Lothian Coalition of Disabled People (LCDP) -and many others - the Lothian Centre for Integrated Living came into being. The first such organisation in Scotland.’ These groups were ‘harnessing the experience and aspirations of disabled people expressed through a democratic forum, as both a catalyst and contributor to processes of change and involvement of disabled people’.* (Dougie Herd – August 1995). Amongst these initiatives, some still exist, including Grapevine, the disability information service which soon joined LCiL.

Right from the start of the organisation, disabled activists made clear that the principles underpinning LCiL’s management and the operation went beyond the legislation of the time. At the inaugural General Meeting, on 18th November 1991, Convenor Douglas Herd declared *that ‘it would empower disabled people in the process of them living independently on their own terms of reference including taking risks.’* It was, and still is, about ‘disabled people taking control of their own lives and the Centre helping them realise that it is possible.’

The clarity and vision developed by these pioneers of the Movement in Scotland, and their ambition, were based on two unique features. Firstly, the user-led model, i.e. the Board of LCiL must have a majority of disabled people on it, the organisation actively recruits a higher number of disabled members of staff, and supported people are actively involved in the development and policy of the organisation.

Secondly, peer support. Peer support is a way of giving and receiving help (knowledge, emotional assistance, or practical help) by understanding others’ situations through shared personal experience. Peer support is built on respect, empathy, shared responsibility, and mutual benefit. When peer support is adequately resourced and facilitated, and these are principles applied, opportunities for self-understanding, self-confidence, and self-growth quietly and powerfully lead to individual and collective capacity to change, and in turn toward self - and collective - determination.

Added to opportunities for self-organising, however, this capacity for change can also lead individuals and groups, originally disempowered, to engage positively with others and together create solutions and changes for the better of all. One crucial condition, however, for a genuine attempt to co-create or co-produce this change is to recognise and be transparent about, underlying power relationships and imbalances at work in the process. The Coalition’s members and the disabled people of today were (and still are), very aware of this.

## Constituting and self-organising as a genuine Disabled People’s Organisation

To move forward with the creation of the new organisation, the Lothian Coalition of Disabled People focused on more administrative tasks through the Lothian for Integrated Living Steering Group. Registered with HMRC from 15th March 1991, the first Articles of Association have a date of 23rd November 1990. The LCiL Co-ordinator post was advertised in November 1990 with the successful recruitment of the first Co-ordinator, Marnie Roadburn.

On 25 March 1991, it was decided that there should be 15 directors (maximum) made up of LILG and LCDP (4 each) and 7 others. The organisation was based at 13 Johnston Terrace, EH1 2 PW.

Beyond the formal constitution of LCiL, disabled people involved in the emergence of the organisation actively engaged with the fundamental questions that underpinned its soul it. Here are some examples:

* On 30 May 1991, it was decided that ‘The Centre should use the term ‘Personal Assistant’ instead of ‘Carer’ and ‘personal assistance’ instead of care.’
* In October 1991, Douglas Herd presented a paper on whether to have volunteers contributing to the organisation. When we know how volunteers can be a cheap option to avoid the cost of professional workers, especially when it may ‘occupy’ some ‘unfortunate’ disabled people unable to have a job, this was not a small question to consider. Staff and members of the Board, therefore, engaged in a lively discussion around what role volunteers would have, how should they be supported, and what was indeed the risk to make up for a not well-resourced Centre.
* During the Away day of 4 November 1991 Board members and staff;
	+ agreed that they would be working on the basis that the disabled person is best placed to define their own needs
	+ Discussed how generally people would understand the phrase ‘peer support’ to develop a shared understanding within the organisation
	+ agreed that they would try to avoid the word ‘user’ for ‘people using the services’ and discussed what should be their rights; for example, how should a complaint procedure be articulated and how their confidentiality should be respected.

On 18 November 1991 at 7.00 pm the AGM and formal launch of the Centre took place in the Hopetown Hall of the Thistle Foundation. Cllr Nolan, a loyal supporter of disabled people was the guest speaker.

Unfortunately also, right from the beginning of LCiL, was the lack of resources and funding, an undermining influence that has greatly disabled the organisation throughout its life, up until today. Already on 5 August 1991, the Steering Group convened an Extraordinary Meeting to discuss difficulties the Centre was having recruiting staff due to the low pay rate (including toward Independent Living Officers (ILOs)). This, subsequently, generated further negotiations with statutory authorities.

Less than a year later the Board of the organisation would carefully discuss the ethical nature of raising funds for LCiL and of charitable donations. On 22 June 1992, the Chair, Dougie Herd, tabled a paper on the issue. It described two different value approaches:

* ‘Ideological fundamentalism
	+ We subscribe to the view that disabled people should have ‘rights not charity’ and therefore should we accept to receive from charitable sources.
* Pragmatisms ideology
	+ If we accept that ‘the end justifies the means should we accept money from any sources’

It was accepted that this question should continue to be assessed while an agreement should be developed with a defining framework. At the next meeting of the Board, against the Chair’s preference, it was agreed that LCiL would approach Telethon…

As the organisation’s Coordinator put it, the first extended year of LCiL *was ‘a challenging the first year but with an enthusiastic and busy professional response, in partnership with….!’* She said later*, ‘Our first year was a challenging one. As the only Centre of its kind in Scotland, we had new ground to break, and high expectations to live up to.’* In addition, she also highlighted the challenging situation for people using the centre. Constant changes in the eligibility criteria of the Independent Living Fund (ILF*) ‘does little to inspire optimism for the forthcoming Community Care reforms.’* She mentioned the many housing issues faced by disabled people and the fact that *‘disabled people are 2½ times more likely to be unemployed than able-bodied people.’*

15 months into the beginning of LCIL:

* The Independent Living Officer had dealt with 58 enquiries about personal assistance, many related to the ILF, but also supporting interviewing personal assistants. 51 enquiries about housing (6 successful) and enquiries about Disability Living Allowance (DLA), many of them signposted to Grapevine, the Disability Information Service, next door physically but not yet part of LCiL.
* The part-time Employment Opportunities Officer supported 42 disabled people and contributed to the successful piloting of an ‘Into Employment’ skills course.
* The administrator and payroll officer had seen his first Centre user in June 1992 and 7 were using the service in November 1992 with more gearing up to come onto it. To those enquiring, an information pack is sent, and if interested a follow-up visit is organised.
* The part-time Training Officer ran training courses for:
	+ 11 Managers of Personal Assistants
	+ 9 trainers
	+ PAs in connection with the Stevenson College waiting for the Scotvec accreditation.

She also set up the Temporary Personal Assistants, for short-term, emergency personal assistance.

Still, in the first annual report, the Convenor/Chair reasserts that*: ‘Being ‘user-led is fundamental to the work of LCIL. So too is recognising the strength which develops when people of different backgrounds and varied experiences work together in an empowering relationship dedicated to objectives set by disabled people themselves. Within LCiL, therefore, the idea of partnership is neither accidental nor second best. Partnership – genuine, meaningful, and directed towards clearly defined goals has been essential to the undoubted success of LCiL.’*

## Scottish Disabled people continued to connect with other disabled people, locally, nationally, and internationally

In October 1991, Board Member Jim Dalgety represented LCiL at a Personal Assistance Conference in Bohn, Germany. Florence Mitchell, also a Board Member, attended the BCOPDP Seminar on Independent Living and Personal Assistance on 7-9 August 1992 in Coventry. She reported an anecdote that shows how, still very much a member of the Independent Living Movement, some disabled people had different views on power relationships. At the event, Colin Barnes (a known theoretician of the Movement) insisted that no PAs would be allowed in the group meetings because on previous occasions PAs tended to take over. Florence, however, feeling that this was discriminating against PAs, still took her PA (including to take notes) and explained why she and the PA would remain silent.

In April 1992, thanks to grant aid sponsorship, a group of 19 people from Scotland representing LCiL, Lothian Coalition of Disabled People, Grapevine, Lothian Right Group, Consultation Advocacy, and Promotion Service (CAPS), and Lothian Region Social Work Department participated in ‘Independent 92.’ To mark the end of the United Nations Decade of Disabled Persons, a major international gathering took place in Vancouver, Canada, between 22 and 26 April 1992. Under the title of ‘Independence 92’, a range of activities was organised to make the event the largest, most significant ‘disability movement’ occasion for many years. More than 3,000 people from over 120 different countries travelled to the event in Canada. They took part in seminars, discussions, and exhibitions reflecting the worldwide movement towards independent living*. ‘It was truly a memorable event for all of us who were fortunate enough to be able to attend.’*

On 2-4 August 1993, Board Member Neil Robinson attended Euro able – 1st European Conference of People with Disability.

## 1992 onwards - Evolving with the opportunities and challenges of the time

The shift of Care in the Community, the de-institutionalisation of people with mental health issues, resonated strongly with LCiL. Funding arrangements had changed, however, and there was a general worry that Social Work Departments were not been given enough resources to implement this significant change and impact on both former patients and professionals to support them in the community.

## 1992 - Conception of the Peer Counselling Service

In 1992, while continuing to provide its various services, and facing a rapidly increasing demand (e.g. 77% increase of people approaching LCiL for Assistance; Payroll demand multiplying by 3, from 7 to 21 people), LCiL managed to find funding for a Peer Counselling Service. Some disabled people, previously institutionalised and not necessarily for mental health issues, were finding the adjustment to a more independent life, especially when employing PAs, psychologically challenging. As such, peer counselling was identified as a need for Independent Living. Within LCiL, the Peer Counselling Support Project provided a peer counselling and support service to disabled people while providing quality training to 10-12 disabled people who had been unemployed for 2 years.

## More relevant and still growing

During the next few years, under-resourced and ‘waiting expectantly, but with scepticism to see what differences the Government’s Disability Bill may bring’, while also wanting anti-discrimination legislation to be enforced by a disability Commission, LCiL continued to face a still rapidly increasing demand.

Very importantly, with some support from Disabled People in Edinburgh, 1995 saw the creation of the second CIL in Scotland and LCiL’s sister organisation, the Glasgow Centre for Inclusive Living.

* 1. saw a positive year of change and growth:
* Reorganisation and expansion of the Independent Living Service. In the annual report of that year, a PA employer describes the importance of training for managing personal assistants*. “[….] My Assistants are like an extension of me. They do everything – chores around the house, help with my work, as well as personal things such as helping me get up, getting washed and dressed, etc. This makes the working relationship and my role as a manager much more complex. The Training that LCiL offers and also the user group meetings have allowed me to meet other people in similar situations. Sharing our experiences has been very valuable to me,”*
* Consolidation and expansion of the Peer Counselling Service – more volunteers (major grant from the National Lottery Board)
* Local Government reorganisation - Increasing number of people using LCiL’s services
* Partnership working internally and externally
* Continued work for payroll (36 employers for 124 PAs) and Edstart training for work with Andrea Bothwell as a User Group Representative.

Despite a lack of continuing funding and amidst a rapidly changing legislative and political environment, LCiL continued to grow steadily.

# Chapter Three - 2000-07

## Change of leadership, strengthening of the organisation in changing times

At the turn of the 21st Century, the Organisation’s coordinator, Marnie Roadburg left LCiL and Hazel Farley took her position.

## 2000-01 - **Building up on the strong organisation**

Interestingly, in the 2000-01 annual report, Hazel mentioned already what would be a continuing challenge for LCIL until today: *‘Achievement of our core philosophy – to be a user-led organisation – becomes more difficult to attain when we have difficulty recruiting disabled people, given their fear of the detrimental impact employment will have on their benefits and hence their quality of life. Another continuing challenge is that of recruiting Personal Assistants. This is due to an unrealistic rate of pay for such posts and the low level of unemployment in Edinburgh as a result of unprecedented economic growth currently being enjoyed by the City.’*

Still, LCiL continued its partnerships and participation in research projects that could only benefit the quality of its services and staff practice. For example, in 2000-01, LCIL was involved in the following:

* ‘Direct payments: the impact on Choice and Control for Disabled People’. Co-authors were Sally Witcher, Kirsten Stalker, and Chris Jones. Research and resultant findings were instrumental in the Scottish Executive extensively funding a direct payment capacity building project in Scotland for 2 years.
* ‘Creating Independent Futures Research Project’ carried out by the Centre for Disability Studies at Leeds University in conjunction with the National Centre for Independent Living and the British Council of Disabled People.
* Peer Counselling Service involved in ‘A pilot investigation into how counsellors might be equipped and supported to work with disabled clients.’ Research carried out by a known counsellor in Scotland as part of her doctorate studies.

## 2002-07 **– Facing major changes in social care externally, strengthening the infrastructure internally**

2002-2003 saw the introduction by the Scottish Executive of free personal care for people over 65. This enabled those who were employing staff privately to receive a contribution towards these costs from social work departments.

Meanwhile, the organisation prepared itself for major changes in Direct Payment legislation over the next three years. From June 2003, local authorities assumed the legal duty to offer Direct Payments to disabled people, under the Community Act (Scotland) 2002. As such, securing in 2003 funding for ‘It’s Your Life’ (a two-year project to support 16-25-year-old disabled people) proved a very wise move.

From April 2004, local authorities had a duty to offer DP to all other community care client groups. The AGM in December 2003 (facilitated by Jim Elder-Woodward) focused on the impact of opening up Direct Payments to other community care groups and the potential implications for LCIL as a user-led disability organisation.

While continuously adjusting to the ever-changing and demanding environment, the organisation was also facing some difficult times. In 2003-04, LCIL experienced the long-term sickness of several key staff in the organisation. Worryingly, funding for training came to an end at the end of March 2004. Yet in this very month, the total number of people receiving Direct Payments in Edinburgh and the Lothians reached 154, an increase of 34% on the previous year.

Strategically tuned, LCIL ensured that IT equipment was upgraded and networked. Payroll software was also networked, resulting in an improved service for payroll users and allowing access to Inland Revenue Online for the first time.

In February 2004 LCiL welcomed the Romanian Minister for Disability to Norton Park

## 2004 - **Grapevine becomes LCiL Disability Information Service**

In April 2004 Grapevine, the Lothian Disability Information Service formerly managed by The Lothian Coalition of Disabled people (LCDP), was transferred to LCIL. LCIL was able to retain Grapevine’s existing staff and incorporate enhanced information provision into LCIL’s ultimate aim to deliver a range of services as identified within the Seven Needs of Independent Living.

## Facing a growing demand without necessary resources

More than ever, LCiL finances were under strain. The audited accounts 2004-05 reported that*: ‘Despite a 40% increase in the uptake of direct payments across the Lothians, funding from local authorities has not increased in line with the demand for LCIL’s services.’* LCIL was therefore looking at developing a social enterprise element, securing funding to *‘examine the feasibility of selling some aspects of Independent Living Training to a wide variety of organisations across all sectors’*. 2005 marked the end of the It’s Your Life Transforming Lives project.

Meanwhile, from 2005 Midlothian Council had awarded a block grant to cover the provision of independent living, payroll and training services to a pre-determined number of existing and new service users for a year, even if every year the future service provision in this local authority area remained unclear.

Although the Scottish Executive announced an additional funding settlement to Local Authorities for 2006/07 (£1.8 million) and 2007/08 (£2 million) to *’further the Direct Payment agenda’*, LCiL never really saw this money. With demand for our services continuing to increase, this placed us under even more financial pressure.

At the end of March 2006, in the last 12 months:

* The Independent Living Service had supported 186 people
* The Peer counselling Service had 12 volunteer Peer Counsellors who had provided a total of 700 hours of counselling to 68 disabled clients. Three further Peer Counsellors had completed their Diploma Certificate in Counselling, bringing the total number of Counsellors qualified to the Diploma level to 8. Yet the service was facing its imminent closure due to lack of funding
* Grapevine had had 1,835 contacts. In that year the Scottish Parliament’s Disability Inquiry by the Equal Opportunities Committee highlighted ‘information’ as the key to providing access to employment, education, and leisure opportunities for disabled people.
* Payroll service had seen an increasing demand of 29% with 182 PA employers using the service.
* The Training Service, in March 2006 saw the start of the Scottish Executive project to capacity build other Scottish support organisations by developing a transferable and comprehensive Training Pack to be disseminated to Direct Payment Support organisations Scotland-wide. This was in addition to funding received from Lloyds TSB to deliver 2 Living Choices courses per year until 2008.

## Collaborative work and partnership remain a core aspect of LCiL

Despite a stressful and unsupportive financial environment, LCiL continued its partnership working:

* With SCDPSO, which represented Scottish Direct Payment Support Organisations
* LCIL was closely involved in the inception of Forth Valley Direct Payments Support Services, including providing advice and training for the staff.
* Delivered training to Fife Direct Payment Support Service
* Assisted DP Caledonia, a DP support organisation in the North of Scotland, with the recruitment process for a new training officer, providing the person with induction.
* Grapevine Co-ordinator joined the Board of UPDATE, Scotland’s national disability information service.

**From 2005 onward** -the external environment in which LCIL Operates is evolving and changing rapidly

Throughout its history, two key characteristics of LCIL have been its:

* Strategic, outward-looking approach to its development, to better serve its community and, partially, to enable its strategic credibility
* Its strong knowledge of the external environment it operates in.

From 2005 onwards, at both UK and Scotland-wide levels, significant policy and legislative developments were raised, pertinent to the future of LCIL, namely:

* Prime Minister’s Strategy Unit policy paper, ‘Improving the Life Chances of Disabled People’ (January 2005), advocated that ‘the centrepiece of this strategy must be the promotion of independent living’ and ‘Disabled People should be at the heart of these initiatives.’
* The report recognised that a new approach to supporting disabled people was now needed and this should focus on the promotion of independent living.
* Lord Ashley’s Disabled Persons (Independent Living) Bill - This Bill, which had now completed its legislative passage through the House of Lords, set out key principles for local authorities, the health service, and other partners to help make independent living a reality.
* Welfare Reform Bill. The Welfare Reform, which had now received Royal assent, was an ambitious Government project, led by the Department for Work and Pensions that aimed to significantly increase the number of people going or going back, to work. Main leverages to achieve this included the reform of housing benefits and replacing incapacity benefit and income support with the new employment and support allowance. Disabled people were one of the groups directly targeted by the reform.
* Disability Discrimination Act (DDA) 2005 - Disability Equality Duty. Amended the DDA 1995, which was the foundation stone of modern disability discrimination law, although it did not use the Social Model definition of Disability, by including the Disability Equality Duty. The DDA prohibited discrimination against disabled people in Employment; provision of goods; facilities and services; selling, letting, or managing of land or premises; and Education.
* Scottish Parliament’s Health Committee’s Care Inquiry – Direct Payments – Final Report November 2006.
* Scottish Parliament’s Disability Working Group Report – November 2006 whose aim was to, ‘establish priorities for the Scottish Executive and partner organisations to promote equality for disabled people in Scotland, and to develop proposals on longer-term mechanisms for engagement with the disability sector.’
* Scottish Parliament’s Equal Opportunities Committee Disability Inquiry: Removing Barriers and Creating Opportunities – November 2006. This inquiry attempted to identify the various barriers facing disabled people in their everyday lives. It focused particularly on barriers within Further and Higher Education, Access to Work, Leisure, and the Arts.
* The “Changing Lives”, 21st Century Social Work Review (2006) advocated the development of flexible and localised service delivery and facilitation of more empowered users of services.
* Adult Support and Protection (Scotland) Act 2007. Aiming to offer greater protection to ‘adults at risk’ of abuse by emphasizing support and protection. It sought to introduce several measures to more strongly/adequately intervene in situations of perceived risk.
* Forthcoming new national guidance on self-directed support (direct payments) in July 2007. LCiL was represented on the Working Group for this.

# Chapter Four - 2007-08

## The year of internal and creative changes, and transition to a new leadership

Fully aware of this environment, as well as the opportunities and challenges it brought and the power games at play within it, LCIL continued to face and respond to the increasing demand. The organisation, always looking at ‘the bigger picture’ and ahead, sometimes took risks to continue to deliver the support it considered essential to disabled people and their aspiration for living more independent lives. A good example is the evolution of the Peer Counselling Service.

## ‘**Your Call’ – The first National Telephone Peer Counselling Support Service in Europe**

At the end of March 2006, due to funding difficulties, the Counselling Service closed in its previous form. Many of the 12 counsellors found volunteer work in other contexts, mostly counselling or counselling related. The Co-ordinator was retained by LCIL for 2006-07, with the twin aims of seeking funding to restart the service (in conjunction with the LCIL Manager and the Capacity Building Co-ordinator) and of running an interim crisis service. The interim service aimed to support the other LCIL services by working with service users in crisis through brief therapy. The coordinator was assisted by one other staff member, an ex-Peer Counsellor, who also saw clients.

Twelve clients were seen in this way over the year. In addition, LCIL was successful in gaining funding from the Scottish Executive to restart the counselling service as a telephone counselling service covering the whole of Scotland in 2007-2010. ‘Your Call’ opened on 28 January 2008. With a large-scale e-mail, postal, and personal contact publicity campaign, including an appearance on STV’s `Scotland Today,’ `Your Call’ had received its first 16 enquiries by the end of March 2007, leading to ongoing counselling sessions for 10 people – about 40 hours a month of counselling contact. The aim was to work with 70 people in the first year of operation.

At the time, internally, LCiL saw some changes at senior management levels. In October 2007, in the absence of the Manager, Sandra Main (Operations coordinator) and Florence Garabedian (Capacity Building Co-ordinator) stepped into the managerial position. In conjunction with them, the Board undertook a strategic review of LCIL with the help of a consultant, which led to the development of a strategy implemented in 2008-09.

# Chapter Five - 2008-12

## Moving towards Self Directed Support and becoming a valued actor of change

The re-articulated direction and vision, along with the decision of the Board to appoint Florence Garabedian as interim CEO from April 2008, brought some stability to the organisation and created space for generating and liberating renewed energy among all staff. As an organisation well regarded by those who knew about it, in a good financial position compared to many other voluntary organisations, and with some interesting developments to be completed, the organisation was favourably placed to harvest the hard work of previous years and start on a new footing. The Annual Report 2007-08 (designed in 2008) titled ‘We can do it!’, produced with input from almost all staff and cheekily looking at the year in the style of a 1950s magazine, very much reflected the start of a new era for the organisation.

In 2007-08, in addition to setting up the new National Peer Counselling Telephone Service, the Training Team completed the training Resource Pack. Thanks to Scottish Government funding, LCiL produced the pack consisting of materials to run courses on Independent Living and Direct Payments, as well as employer Skills and Training for Personal Assistants. The project team ran a series of events around the country for all Direct Payment Support Organisations and relevant Authority groups to promote it.

## Despite a new economic crisis 2008 marks many new developments for LCiL

Although worldwide, another economic crisis was looming, threatening in Scotland any positive outcomes achieved in previous years, in the field of social care and other areas, a renewed focus on Independent Living was emerging within the Scottish Government. The country had seen the new merged Commission for Equality and Human Rights established in October 2007. Meanwhile, the ‘National Guidance on Self-Directed support’, providing a framework for implementing SDS was published.

As the impact of the crisis unfolded:

* The Government-led Review of Independent Living in Scotland established a national Core Reference Group on Independent Living (on which LCiL was represented) tasked with bringing together all stakeholders from statutory, non-statutory, and voluntary sectors, including disabled people, from the Independent Living Movement
* 2008-09 was the year of the launch of the Independent Living in Scotland project (ILiS). In January 2009, LCiL and ILiS jointly organised a Lothian event, exclusively for disabled people, to raise awareness of Independent Living, of how to take part in the Independent Living Movement, and to promote ways of becoming actively involved. On 8 December 2009 the Scottish Government, the Convention of Scottish Local Authorities (COSLA), and the Convenor of Independent Living in Scotland (ILIS) will sign up to a ‘new shared vision of independent living for disabled people in Scotland,’ whereby disabled people across Scotland will have equality of opportunity and enjoy the same freedom, choice, dignity, and control that other citizens take for granted, at home, at work, in education and the social and civic life of the community.

A few months earlier, LCiL launched a 3 years strategy based on 4 guiding aims:

* LCiL is a well-resourced organisation
* LCiL is a modern and innovative organisation that provides ‘individual services’ and a ‘one-stop-shop
* LCiL develops, sets, and maintains standards of excellence
* LCiL is an independent, strong value-based, pro-active organisation that leads the future on ‘Independent Living’ and works in partnership with other organisations.

In March 2009 the organisation relaunched:

* With the new name of ‘Lothian Centre for Inclusive Living’ (LCiL) replacing ‘Lothian Centre for Integrated Living.’ The change reflected the ethos and direction of LCiL. Generally, ‘integrated’ was no longer used as a term meaning that people are included as a valued individuals within a bigger group. ‘Inclusive’ better reflected the idea of openness and acceptance to people as they are. It asserted that disabled people have the right to be included in the community and that for this to happen the community should provide the necessary support. It meant to be included by accepting difference, not seeking to make a person fit in.
* A logo and mission statement. The new mission statement reflected that LCiL worked for equality for disabled people: ‘LCiL works with disabled people to take control of their own lives, support their choice to take up their rights and enable their full participation in society.’
* A new website
* A new membership scheme

Your Call, the National Telephone Peer Counselling Service was officially launched on 2 December 2008 at the Hibernian Stadium. Jointly hosted by LCiL and NHS Lothian.

In partnership with Inclusion Scotland and GCIL, LCiL got involved in the development of a comprehensive training standards framework proposal for future Disability Equality Training (DET) in Scotland.

Through its support to, and as chair of, Self-Direct Support Scotland (SDSS – the umbrella organisation of self-directed support organisations replacing SCDPSO ), *‘LCiL is committed to raising the voice of user-led organisations and ensuring that direct payments remain a viable tool towards Independent Living.’* In 2009 a member of LCiL staff was seconded to the organisation.

LCiL also actively participated in the Scottish Alliance for Independent Living (SAIL) which included other large, although not necessarily user-led, organisations working in the field of disability.

## The seed of a ‘Payroll enhanced service’

Pioneering new projects and responding holistically to disabled people’s expressed needs was a continuing goal for LCiL. The work alongside Edinburgh City Council on their Edinburgh Card (as a new means for DP recipients to receive their payments) was a good example. Following this experience, LCiL was thinking about new models of support - financial management support in particular - that could be offered to those who either could not manage the financial and administration of their DP or who would be interested in buying this particular support.

The main difficulty with this particular development was the lack of direction within local authorities (which would fund the support within DP packages). It was still extremely difficult to identify what kind of support disabled people would need in the future or be able to purchase because they did not know what the national personalisation and self-directed support agendas would mean for them locally. Also at the time, the banks did not seem to be flexible enough to allow organisations such as LCiL to access certain types of accounts or banking facilities. LCiL, however, saw this development as a key factor to a successful self-directed support/DP strategy, locally and at a national level.

In 2010-11, Disabled people continued to experience policy and legislative changes that impacted them directly as well as their organisation. The Comprehensive Spending Review that took place in 2010 had led to the Welfare Reform that consequently affected a significant number of disabled people, people with long-term conditions, and older people (people LCiL work with). People were told that by 2015:

- The Independent Living Fund would no longer exist as it was

- Disability Living Allowance would no longer exist and be replaced with a new benefit the Personal Independence Payment (PIP). The whole budget for this would be cut by 20% (around 800,000 claimants to lose their DLA)

- The Incapacity benefit would no longer exist. All claimants would have to go through a medical assessment and move on to employment Support Allowance or Job Seekers Allowance.

- Housing benefits would be heavily restricted

- 3.5m disabled people in Britain will have lost over £9.2 billion of critical support

In the meantime, from 1 October 2010, the Equality Act 2010 harmonised and replaced previous anti-discrimination laws and legislation (such as the Race Relations Act 1976 and the Disability Discrimination Act 1995) with a single Act. The Equality Act covers the same groups that were protected by existing equality legislation – age, disability, gender re-assignment, race, religion or belief, gender, sexual orientation, marriage and civil partnership, and pregnancy and maternity. Many disabled people, however, felt that this merging of rights was no longer covering some very specific circumstances that indirectly harmed their rights.

Meanwhile, the move to self-directed support legislation had started:

* In 2010 the Scottish Government consulted on and published its Self-Directed Support National Strategy for Scotland. LCiL was represented on various implementation working groups
* In 2010 The Scottish Government consulted on its Draft Self Directed Support (Scotland) Bill and set up a Social Care (SDS) (Scotland) Bill Expert Steering Group, on which LCiL was represented.

In this context, LCiL finalised new models of support, financial management support in particular that could be offered to those who either could not manage the financial and administration of their DP or who simply would be interested in buying this particular support. To this end, LCiL moved its current account to a different bank so that the organisation was able to hold accounts on behalf of people and manage the financial side of their care/support package.

Externally LCiL remained actively involved in the Government’s review of Independent Living in Scotland through the Independent Living in Scotland (ILiS) project and the Core Reference Group. Very active in the Group, LCiL was particularly involved in progressing the portability of care agenda, i.e. find ways of addressing the multitude of barriers that prevent people in receipt of care/support from moving from one area to another, either for work, family commitment, studying, etc.

Highly active on the Steering Group of the Independent Living in Scotland (ILiS) project, LCiL was able during this period to take part in important policy discussions (e.g. the UK comprehensive funding review, the Scottish budget review). In addition to this, ILiS proved to be a great source of information and reference to shape LCiL’s policy position or responses.

Locally, LCiL was also involved in important developments and brought an enthusiastic, professional user-led approach to them while being increasingly recognised as a valuable, even if challenging, partner by local authorities (particularly within the CEC Commissioning Strategy for Care and support and Commissioning plan for adult care and support services Checkpoint Group and the Personalisation and Outcomes Checkpoint Group (since April 2011))

In 2010-11, LCiL’s Board of Directors commenced a comprehensive review of the organisation’s budget allocation, development trends, and organisational structure. This was to consider future pension provision, organisational developments and better respond to the possible introduction of new models of service delivery within the changing funding environment.

# Chapter Six - 2012-16

## Moving towards Self Directed Support (SDS) in different ways brings LCiL internal and external activities to new levels

By 2011-12, although many organisations, care providers, in particular, may have not engaged with the future legislation, it was clear that the coming SDS Bill would force local authorities to offer SDS systematically to the majority of people eligible for care/support.

The most important change directly impacting LCiL service users and the organisation would be:

* SDS consists of 4 options
* Option 1 - a direct payment
* Option 2 - The responsibility of the financial management of the individual budget remains with the local authority whether it directly manages it or it delegates the task to a third party
* Option 3 – A direct service
* Option 4 – A combination of the above.

Very much involved and aware of all developments, LCiL was able to increase its engagement with Lothian local authorities and direct care providers around the issue. Concurrently, local authorities’ interpretation of SDS, aggravated by the idea of a Resource Allocation System (RAS), advocated at the time by In Control Scotland, raised concerns amongst DPOs. This was in addition to an increasing market approach that was threatening Disabled People’s Organisations’ quality of service and adequate levels of support for people with a DP. Actively involved in all of this, LCiL was also heavily involved in the Independent Living Core Reference Group, set up by the Scottish Government to review Independent Living in Scotland.

## The SDS Development Programme or how LCiL developed a whole new limb and connected differently with its Disabled people’s Organisation identity

When, in December 2011, LCiL secured funding from the Scottish Government to run a 3 year Self Directed Support (SDS) Development Programme from 2012-2015, this unexpected resource opened up an opportunity to be even closer to its DPO aspiration. The organisation would be able to support capacity building and peer support to flourish within the organisation. It would enhance its capacity to respond pro-actively and effectively to the changes, challenges, and opportunities brought by the SDS Bill and the SDS strategies. The resulting programme, based on shared objectives with GCIL would enable LCiL:

* To individually develop a strategic response to local SDS developments across Lothian and ensure that its future support/information services meet the local demand effectively and creatively. This combined effort with GCIL will enable the two CILs in Scotland to take a co-ordinated approach to develop support/brokerage models
* in partnership with GCIL, to develop and pilot a web-based SDS support service management system that meets the changing needs of SDS support organisations and service users in Scotland.

Fully integrated within the four strategic aims of LCiL, the programme aimed to ensure that the organisation would be fit for purpose when local authorities themselves rolled out SDS. It consisted of capacity building activities in the following areas:

* Users involvement
* Services suitability and relevance to demand
* Policy influencing
* Fit for purpose systems and internal policies
* Resource capacity management
* Financial sustainability

## The Champions Programme

In 2012-13 LCiL liaised quite extensively with the Office of Disability Issues (ODI) and the Department of Work and Pensions (DWP) to secure funding for 2 projects. One was the Champions Project (the other was for Your Call). Subsequently, combining two years’ funding from the Office of Disability Issues (ODI) and Scottish Government SDS Development programme funding, the SDS Development Programme trained and equipped a group of disabled people, people with long-term conditions and carers, as Champions who promoted understanding of Independent Living and SDS, and raised the profile of LCiL and Disabled People’s Organisations.

Each of the nine Champions had a Buddy who was a member of LCiL staff and who supported them to carry out their role. Champions met together regularly to share learning and formed a strong peer support group. During its first year of operation, the programme became an integral part of LCiL and was instrumental in influencing how SDS was implemented.

Through their continuing hard work and commitment to the organisation, the Champions were able to make a significant and valuable impact on the way local authorities (and other organisations) developed their policies, delivered staff training and development, and raised awareness via user involvement, etc. By ‘telling it like it is,’ the Champions engaged professionally with representatives of statutory and non-statutory organisations, voluntarily for LCIL.

## Setting up the Financial Management Support Service

In 2011-12, LCiL also secured funding from the Innovation Fund and the Enterprise Growth Fund toward the set-up of the Financial Management Support Service. The funding enabled the payroll service to test the market and get organised to hold and operate ‘client bank accounts’ on behalf of service users in receipt of a direct payment. The service could then help make payments for chosen purchases (e.g. direct care providers, an agency, or personal assistants’ salaries). It also administered other funds received to pay for care and support. The service could be tailored to suit each individual’s circumstances and enabled people with less capacity to access and benefit from flexible support without struggling over how they managed this. At the end of March 2013, 28 people were using the service. By the end of 2014, there were 64.

## Training

If not on the same scale, all services were facing increased demand year on year and had to grow despite no increases in funding or resources. In 2012, the Training service, in addition to running 11 training courses over 27 days with 81 participants, and without extra funding, had to update the LCiL’s Training Resource Pack due to the introduction of the PVG Scheme and the new Equality Act 2010. The service piloted a scheme to enable participants to obtain Individual Learning Accounts (ILS) to fund places on the Training for PAs courses, which worked for a few years. By the end of 2013, the Training Service was able to expand the training courses offered to disabled people by developing a new Introductory Health & Food Safety Course. This course, co-delivered and co-designed with Greggs the Bakers, was designed specifically with disabled people in mind, to give them the confidence and skills to choose healthy eating options and safely prepare food. It was rolled out and delivered in 2013-14. In return, LCIL agreed to develop and deliver a Disabled Equality and Etiquette Session for the Greggs (Scotland) Team.

## The Living and work Choices Programme

This programme, funded by the Big Lottery (BIG) for five years, commenced in 2012-13. It consisted of the delivery of a training programme with disabled people and people with long-term conditions who had not yet considered, or were about to explore, more independent ways of living their lives. Very importantly, the Programme offered one-to-one support and person-centred planning so that individuals could translate their learning and outcomes into action. The programme offered:

- Two ‘Living Work Choice’ four-day courses

- One ‘Essential Employer Skills’ three-day course

- It also offered several free places on the training for PAs courses, mentioned earlier for other people interested in PA employment and not able to use ILAs.

## The Grapevine Example

In addition to an increasing number of queries, the continuation of talks and presentations, the participation in a short information film, benefit checks, and establishing links with the Scottish Parliament’s Welfare Reform Group, Grapevine started what would become a long-term relationship with what was called at the time the Gateway Service. From 14 March 2012, Grapevine provided two out-reach surgeries per week, at Craighall Resource Centre and Firhill Resource Centre. The scheme, coordinated by the City of Edinburgh Council, targeted those who were newly diagnosed with neurological conditions in Edinburgh. Although Grapevine worked very strategically and enhanced the CEC’s new joint approach towards more coordinated and accessible care in Edinburgh, it was still a battle to be considered as an equal partner and the service did not receive any extra funding for it.

## The staff pension example

Under increasing financial pressure and facing significant liability, the Board took the decision, in February 2012, to stop any new members to the Lothian Pension Fund. Soon after the Board agreed that withdrawing from the Lothian Pension Fund may be the best solution to secure a more sustainable financial future for the organisation. To this end, information and the expertise of 2 consultants were sought to develop a proposal for a change of pension arrangements. The resultant proposal presented to staff in July 2012 included:

* ceasing membership to the Lothian Pension Fund
* setting up a new defined contribution pension scheme that would be offered to all staff.

## The closure of the Peer Counselling example

Another significant setback, despite a very dynamic and intense fundraising campaign, was the closure of Your Call in 2013. This was primarily due to the Scottish Government’s inability to co-ordinate a proper funding programme for services working nationally within the mental health sector, resulting in such organisations having to negotiate with each local health board for core funding. Given the nature of the Your Call service, engaging with service users who need to have the assurance that their support would be maintained over several weeks, and in the absence of secure core funding, the service was forced to close in July 2013. Its Coordinator and Administrator were made redundant and the disabled volunteer counsellors, much valued and thanked for their years of dedication, commitment, and hard work were, where possible/desired, referred to other agencies to continue their work. This service was a major loss to the organisation.

## Some positive developments

Despite difficulties, LCiL continued to question its own identity and connected with change.

In 2013, LCiL developed a closer and long-lasting working partnership with VOCAL (Voices of Carers across Lothian). Staff from the two organisations attended each other’s full staff meetings and ran reciprocal training sessions aimed at improving the ability of both organisations to make referrals to each other. Working so closely, and happily, with a carer organisation was new and against a historical mistrust of carer organisations. However, still aware of how carers and carer organisations had collectively much more power in society, and were better perceived in the wider public, and also aware of ambiguities around the carer and ‘cared for’ relationship, LCiL, and its staff, in particular, were able to build an important and historical bridge that thrives to this day...

In October 2013, the new LCiL website was formally launched with a new structure and refreshed branding to make it easier for online visitors to access information and advice on all LCiL services /support, including a series of updated and new factsheets available for free download from the online E-library.

Meanwhile, LCiL’s Chief Executive continued to be closely involved in the development of a national monitoring and evaluation framework for support organisations called ‘Support in the Right Direction.’ The group of six organisations leading on the initiative, coordinated by Evaluation Support Scotland (ESS) and funded by the Scottish Government, produced a valuable tool that includes interesting and quality case studies produced by LCiL.

## 1st April 2014 **The SDS (Scotland) Act 2013 has been enacted and imposes a duty on local authorities to systematically offer SDS to the majority of people accessing social care. LCiL takes centre stage!**

At the request of the Scottish Government, LCiL organised the launch of the SDS Act in Scotland which gathered 100+ disabled people, people with long term conditions, older people, and representatives of statutory and non-statutory organisations. LCiL took the brave step of web-casting the official event from its website homepage which attracted around 50 viewers across Scotland. This also provided a basis for social media engagement during the event via the Twitter feed, which was projected live relaying people’s posts.

Locally, SDS generated a lot of activities, and LCiL champions or staff actively participated in Lothian local authorities’ policy developments, training sessions, consultation exercises. Disappointingly, however, LCiL’s attempts to share with local authority colleagues a reflective approach embedded in practice failed. It was increasingly felt that local authority staff were overwhelmed by the level of change, their heavy and wide workload, and by having no space to properly monitor or reflect on achievements.

During that year, LCiL’s CEO, also Chair of SDSS, co-chaired with a Scottish Government colleague, and provided leadership to, the Independent Living Fund Scotland Project Board, overseeing the change from UK Independent Living Fund (ILF) to the Scottish-wide organisation, including the smooth transfer of 3,000+ members’ funds on 1 July 2015. The Scottish Government, in co-production with Disabled People Organisations (DPOs) and other organisations, had committed to setting up a new Scottish ILF (ILF-Scotland) which commenced on 1 July 2015. All current ILF recipients were successfully transferred into the new ILF-Scotland. Thereby ensuring continuity of their funding and support. The Scottish Government also committed to opening ILF Scotland to new recipients and made £5 million per year available for this.

## Internally LCiL never ceases to question itself, adjust and change

Strategically, in 2014-15 LCiL strengthened its relationship with NHS Lothian and explored 2 specific partnerships which came to fruition in 2015-16, supporting people with Chronic Obstructive Pulmonary Diseases (COPD) and carers of people using the reduced Lanfine Unit in Edinburgh. These projects are still active to this day and have opened the door to more successful relationships with NHS Lothian in the future.

While services continued to grow due to increasing demand, the renewal of 3 years of funding for the SDS development programme (2015-18) enabled LCiL to strengthen its capacity and work on its practice. In 2015-16:

* LCIL developed a strategic response to local SDS developments in the Lothians and to ensure that future support/information services could meet the local demand effectively and creatively.
* The organisation continued to review staff practice about the individual outcome-focused approach which is integral to SDS. To this end, near the end of the financial year, LCiL was able to offer to all staff the Good Conversations training programme developed by the Thistle Foundation, the ALLIANCE, and Government Joint Improvement Team (JIT).
* The LCiL senior management team made the most of the U.Lab Massive Open Online Course (MOOC) that was shared across the world through local hubs including one in Norton Park Centre.
* LCiL offered all staff the opportunity to attend guided mindfulness sessions and learn how to use this tool in both a professional and personal capacity. This was in recognition that staff and volunteers should be supported with the fast pace of change and the many challenges they face daily.

## Meanwhile, LCiL kept growing

* While leading on SDS, dealing with an ever-changing environment, LCiL services continued to grow. At the end of March 2016, during the last 12 months:
* The Independent Living Service had supported 551 people (64 more than the previous year)
* Training, having secured funding from Scottish Government (Innovation Fund) and the Robertson Trust for three years (2015-18), the Training Service had continued to provide a variety of courses relevant to Independent Living, enabling a positive learning experience, facilitating the development of new skills, widening opportunities for disabled people to increase self-confidence, peer support and to expand their existing knowledge of Independent Living. It also offered DET to external organisations.
* The SDS Development programme, having changed its project model, had offered capacity-building workshops and peer support groups to disabled people/people with long-term conditions and parents and Carers. It had also taken part in a collaborative assessment programme. This was a six-day programme to give assessors and people with experience of assessing the opportunity to work together to co-produce guidance on how to make social care assessment more collaborative, as required by the SDS Act. Two Champions were involved as participants and assessors came from six local authorities.
* Payroll - during the 2015-16 year, the demand for the service grew by 17%. A total of 609 disabled employers made use of the payroll service. In addition to the increased take-up of payroll and FMS services, the advent of Pension Auto Enrolment resulted in additional resources/investment being put in place, not only to meet the increased take-up but also to ensure LCIL had the infrastructure in place to support all its payroll service users with their legal obligations under the new pension legislation. Roll out of Pension Auto Enrolment commenced in June 2015 (5 service users) with a further 29 service users staging between January and March 2016.
* The Financial Management Service (FMS), formerly referred to as enhanced payroll service, also saw an increase in demand. During 2015-16, a total of 126 payroll service users accessed this support. A further 28 (non-payroll) service users also took up the FMS to engage with Agency support and or make other payments from their SDS budgets.

Grapevine - In 2015-16 the Grapevine Disability Information Service had enquiries for advice and information from 1198 individuals and organisations in Edinburgh, East Lothian, and Midlothian. A further 234 people received information/advice via outreach presentations. 56 benefit checks (Attendance Allowance, Pension Credits, and other entitlements) for people aged 65 and above living in the City of Edinburgh were carried out in the period.

In March 2016, day services for physically disabled people provided at Firhill and Craighall day centres were transferred to the Longstone Resource Centre. Edinburgh Community Stroke Service, rehabilitation support services, occupational therapy, speech therapy, physiotherapy, a technology hub, group support such as Lifestyle Management courses, were now provided from Longstone and Grapevine continued to provide outreach and a referral process with the services based here.

Meanwhile, the small grant received from NHS Lothian enabled home visits to be provided to isolated individuals with Chronic Obstructive Pulmonary Disease during 2015-16.

Still very much involved in policy development and engagement with the Independent Living Movement, in July 2016, in collaboration with SILC, LCiL invited Cabinet Secretary Shona Robison to launch the ‘Our shared ambition for the future of social care support in Scotland’, a major document co-produced by a large number of national and local voluntary organisations.

# Chapter Seven - 2016-20

## Pension Auto-Enrolment

Pension Auto- Enrolment proved to be a huge undertaking for the Payroll Service and has added complexity and time to the payroll process. As ever, the service planned and prepared for this. However, engaging with each of the 600+ single payroll service users on such a dry and often misunderstood responsibility, took more than a full-time post allocated to it. Easing the new duty on PA employers, by more or less taking control of it on their behalf, creates a real headache for the service. Still, subsequently, as the representative of the leading organisation on Pension Auto-enrolment for PA employers, and in partnership with SDSS, the LCiL Operations Co-ordinator was the speaker at an event and Webinar that provided vital information to local authorities, Scottish Governments, and other interested organisations.

## Tender of LCiL core services in Edinburgh

One afternoon in November 2015, as part of the review of our core services by The City of Edinburgh Council, 15 service users gathered and powerfully explained to 3 Council Commissioners how and why they valued their organization, including the user-led and peer support elements crucial to it. At the time, it seemed that this conversation profoundly impacted CEC colleagues’ understanding of the value of user-led organisations and peer support. However, following the review of LCiL core services, and despite a clear message about the risks of destabilizing the organisation, LCiL was warned that CEC would put these services out to tender. Although the Self Directed Support (SDS) (Scotland) Act 2013 mentions the need for support to be made available to SDS recipients, the increasing ‘market approach’ did not necessarily favour user-led support organisations such as LCiL.

In June 2016 the organisation saw all its services (Independent Living Service, Payroll Service, and Grapevine) tendered in Edinburgh. The outcome of this tender became clear only in December 2016. LCIL retained the contracts for the Independent Living Service and Grapevine, albeit with different service specifications, fewer hours of services, and less funding. Uncertainty regarding the outcome for the payroll service remained even longer, as the new framework agreement could not be signed before March 2017. From April 2017, LCiL’s Payroll Support Service was part of a framework with two other mainstream payroll providers which are not based in Edinburgh or the Lothians. Under this new framework, CEC provided funding directly to Direct Payment recipients, enabling them to purchase payroll support directly from their chosen provider, whereas in previous years CEC funded LCIL’s payroll service partly via block funding as part of SLA and partly via funds provided directly to DP recipients.

LCiL changed its charging structure – formerly charging PA Employers based on the number of PAs wages processed, now charging a fixed monthly or four weekly fee to each PA employer. Under the new framework agreement, existing DP recipients were now funded at a rate charged by LCiL, however, at the point where the PA Employer has his/her care package reviewed, CEC would reduce the level of funding to cover payroll costs to that of the cheapest provider on the framework. From 1 April 2017, all new DP recipients in CEC were funded at this cheapest rate.

As LCiL was based in Edinburgh, where generally financial services are significantly more expensive to run, and as it provided a fully accessible and flexible service tailored around the needs of each individual, the organisation was not really in a position to compete with the two other mainstream services, based in Fife and Durham. As a result, LCiL monitored the even more closely the service and considered its options long-term.

## Maintaining standards but moving forward

While dealing with ongoing funding issues related to its services, LCiL was also aware of the potential end of Scottish Government funding to DPOs more generally. In March 2017, with SDSS support, LCiL also took the lead in gathering the views of Scottish Disabled People’s Organisations (DPOs) about influencing future Scottish Government funding of DPOs. The event led to a meeting with the Scottish Government in June 2017 that was very much welcomed by all parties.

However, although stressful, time-consuming, and not conducive to forward-thinking, funding issues never seemed to affect the quality of LCiL services.

In April 2017 the Grapevine service was accredited by the Scottish Government as the National Standard for Information and Advice providers – Tier 1.

In early 2018, LCiL produced its Service Users’ satisfaction survey (every two years). With outstanding satisfaction rates, the organisation could be confident that it was maintaining its standards of excellence. E.g. 95% of the people surveyed said that they agree or strongly agree with the statement *‘I value the work of LCiL and would recommend the organisation to others.* 94% also said that they agreed or strongly agreed that it was important to them that LCIL remains a one-stop-shop (provides all services as one organisation).

In the same year, LCiL fully prepared itself for the implementation of the European GDPR legislation in advance of the compliance date. Like many other voluntary organisations, however, LCiL had to invest a lot of time and resources to ensure that the organisation was fully compliant while also being fully engaged in informing its service users on the impact GDPR had on data sharing and management. Furthermore, the organisation successfully engaged in the Cyber Essential Accreditation, bringing an even higher level of security to its systems and data retention.

In March 2018, starting with a very well-attended event, LCiL engaged with its users to further their input and help shape the future organisation's strategic framework. This was followed by a similar event in April 2018, gathering professionals from statutory and voluntary sectors.

In June 2018, LCiL was asked by the Scottish Government to host the event where the newly successful organisations funded by the Support in the Right Direction (SiRD) were announced. Although the Minister couldn’t attend at the last minute, due to a Scottish Government reshuffle on the same day, Scottish Government representatives attended and took time to meet service users who fully engaged with the Government representative.

## 2019-20 seeing the end of the difficult times?

Despite the continuing good feedback from people using LCiL, the many ongoing relationships with other organisations, and with the increasing recognition of the organisation as an important and trusted partner in local and national developments in social care, it was clear at the end of 2018 that the last 2 ½ years had been hard on the organisation and its staff. The insecurity triggered by the tender, the relentless and bureaucratic changes imposed on services, and, possibly, some disillusion with SDS, may well explain why two-thirds of the staff left the organisation during this period.

Since then, new members of staff, however, have brought new energies to the organisation, new skills, and a new outlook on internal and external developments. Yet the focus is still on supporting disabled people, people with long-term conditions, and older people minimising barriers, and supporting self-empowerment.

In the latest survey (July 2020) 92.75% of the people responding to the survey agreed or strongly agreed that ‘Support from LCiL has helped improve my choices and given me more control in my life. 97.25% agreed or strongly agreed that ‘*It is important to me that LCIL remains a one-stop-shop (provides all services as one organisation)*’.

In 2019-20, although LCiL faced major financial issues:

* The Independent Living Team supported 716 people
* The payroll service supported 666 people – around 500 every month
* Grapevine (not including the Welfare Matters project) provided support and information to 349 people through 823 contacts and 2,742 queries. It enabled an extra 8 people to be successful with their benefit claim, gaining collectively an extra £69,314.80 or £8,664.35 per person per year.
* The SDS Development Project offered peer support and information opportunities to a minimum of 161 people, either disabled or carer.
* LCiL delivered 4 Disability Equality Training days for several Scottish organisations.

Very importantly, LCiL enabled individuals to complete the LCiL Champions training programme, and celebrate their achievement with other voluntary and statutory organisations, early in April 2019.

# Chapter Eight - 2020-21

## The year that changed the World and strengthened LCiL towards a new beginning

As the country moved to minimize contact between people, closing businesses and services, reducing support and the care of many. LCiL quickly moved its delivery model to protect its staff while continuing to deliver its services in the most accessible ways possible. As soon as 23 March 2020, all one-to-one interactions took place over the phone or online, and most of the communication and information was also provided in this way. Although a handful of staff members remained working from the office, to support the rest of the organisation working from home and relay paperwork by post to those service users who were not digitally connected, the whole organisation adapted processes, procedures, and ways of working.

The organisation has changed in some ways and many of the new features will probably remain, but its fundamental nature as a DPO embedded in the Independent Living Movement remains the same.

In Scotland, the full impact of this unprecedented global situation is still to be fully understood. It is already known, however, that the UK, although to a less extend Scotland, is in the top league about the number of intensive care situations and deaths proportional to its population. Disabled people, people with long-term conditions, and older people have been those most impacted by it, along with other minorities. What will be done with this information, and similar emerging analysis, is up to all those who can do something about it.

In Scotland, the recently published Independent Review of Social Care, the coming Social Care Standards, and the appetite of many to fundamentally change the system, is encouraging. The coming Human Rights framework adopted by the Scottish Government should also support this. Locally, the Edinburgh Pact and the intention to radically do things differently may also lead to change in the right direction.

For LCiL, at the end of March 2021, following a smooth handover between the departing CEO, Florence Garabedian, and her successor, Lyn Pornaro, there is an opportunity to engage positively with the new emerging environment. With renewed energy and vision, the organisation is in a good place to continue the work, and support the aspirations, of people who just want to be able to live their lives as equal citizens, away from oppression, in a more inclusive society.

Florence Garabedian
CEO LCiL
(1st April 2008-28th Feb. 2021)

22 March 2021