Lothian Centre for Inclusive Living Annual Report 2011/12





Rights & choices for disabled people, people with long term conditions and older people in Edinburgh and Lothian.









www.lothiancil.org.uk



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Introduction

2011-2012 has been a formative year for LCiL. In this Annual Report we will present our key achievements, highlights and lessons learned over the course of the 2011-2012.

The Lothian Centre for Inclusive Living (LCiL) is a user-controlled organisation, managed by a board made up of a majority of disabled people. We provide a range of services to disabled people, people with long term conditions and older people, which enable them to take control of their lives and live independently in their community.

These include:

Support for Independent Living
Providing you with the information
and one-to-one support you need
to arrange and manage your own
Self-Directed Support package.

Payroll Service

Wages processing and related administration for disabled people employing their own personal assistants.

Grapevine – Disability Information Free, confidential information and advice on any disability issue to people in Edinburgh, East Lothian or Midlothian.



Training Service

Free training opportunities for disabled people and competitively priced training for organisations on topics such as Disability Equality and Self Directed Support and Direct Payments.

Your Call - Telephone Counselling
Free telephone and email counselling
service for disabled adults in
Scotland and their immediate family
members or carers.

Independent Living remains at the heart of everything LCiL does. The four fundamental aims of our current strategy are leading LCiL to an exciting future.

These are:

- 1. LCiL is a well resourced organisation.
- 2. LCiL is a modern and innovative organisation which provides individual services and a one-stopshop.
- 3. LCiL develops, sets and maintains standards of excellence.
- 4. LCiL is an independent, strong value-based, pro-active organisation which leads the future on Independent Living and works in partnership with other organisations.

Through this report you will find out how we have been putting these strategic aims into practice over the course of the year. The report is made up of the following:

> Facts and figures on page 5, providing you with a snapshot of our work throughout the year.

> Our short film with Stephan Tait, LCiL service user, and Jeff Adamson, the Chairperson of our Board, provides you with the opportunity to hear firsthand how LCiL has made a difference to them and what their hopes are for the future.



Click here to view this film online.

You can find out more about how LCiL has made an impact on pages 6-7. We also include a profile of each service with specific highlights featuring key initiatives which have been developed during the year from page 8 onwards.

On the next page our Chairperson, Jeff Adamson shares his thoughts and reflections on LCiL's work over the year.



Chairperson's Report

As an organisation our work makes an impact at many levels. Whilst our services respond to the needs of disabled people and people with long term conditions, we influence and engage with those providing services, such as local authorities and direct care service providers, to achieve better outcomes for disabled people.

Nationally our work within the Independent Living Movement and with the Scottish Government champions the

choices and rights of disabled people across Scotland.

We do this in a climate which is increasingly uncertain. Whilst cut-backs are affecting services across the voluntary sector, the biggest overhaul of the UK

welfare system for a generation is on the horizon. This will affect the freedom and rights of disabled people to participate in society fully as equal citizens.

Although such changes are being decided in Westminster, in Scotland, the Self-Direct Support Bill will make it law that all disabled people eligible for care and support should have genuine choice

and control over how this is delivered to them. We are still to see how this will work in reality.

In the meantime we see an increasing 'market approach', which potentially may ignore the long term benefits for and key empowerment of individuals brought by the collective actions and values of user-led organisations and Disabled People Organisations (DPO). Like in the wider society, and although it may enable choice to some, a market approach is not necessarily conducive

of cheaper care and may force individuals to choose between, and compromise over, quality and adequate level of support.

Similarly there will be a much greater risk that the most able people, the most connected, those more assertive

will be able to benefit from the coming marketization of care while others may not. Closely connected to this an important question emerges. Should information and support be a universal and free accessible service to all concerned or should it be dismantled into various components so that it fits the unit costs, fees and various charges that the market approach requires to function? In such circumstances we



Jeff Adamson, LCiL Chairperson

must, and we do, continue to evidence that our services provide best value to our funders whilst tailoring support to meet the needs of people with a wide range of abilities.

Challenging yes, but as an organisation we have a history of adapting and

responding creatively. This provides us with real means to influence, inform and develop relations with those who drive change.

We look forward to working with our partners over the course of the coming years.

What our service users have to say...



- **>** Over three quarters of our service users agree or strongly agree that 'the support I get from LCiL helps me to live in my own home....'
- **>** Over 90% of our service users value the work of LCiL and would recommend the organisation to others.
- **> 8** in 10 agree with the statement 'support from LCIL has helped my choices and given me more control in my life.'

- > 97% have confidence in the competence and knowledge of LCiL staff.
- **Three quarters** also agree with the statement 'as a result of support from LCiL, I have been able to do other things that are important to me.'
- **>** 9 in 10 agree that 'the service(s) met my needs within a reasonable and appropriate timescale.'
- **> 95%** agree with the statement 'the LCiL service(s) I used fulfilled my expectations.'

These statistics were gathered as part of LCiL's Service Users' Survey 2012. See here for the full version of the survey.

Strategic focus throughout the year 2011-2012

Partnerships

- ➤ LCiL's Chief Executive worked closely with Self-Directed Support Scotland (SDSS) on developing and raising funds for the current SDSS programme of work.
- An active member on the Steering Group of Independent Living in Scotland (ILiS),LCiL was able to engage positively on national issues such as the Welfare Reform, Self Directed Support legislation and, currently, the integration of health and social care.
- > Through the Independent Living
 Core Reference Group, set up by
 the Scottish Government to review
 Independent Living in Scotland, LCiL
 highlighted that many disabled people
 experience a postcode lottery in
 relation to their care packages.
- ➤ Locally, LCiL put forward the views of disabled people and people with long term conditions on a range of planning groups, including:
 - City of Edinburgh Councils (CEC Check Point Group on Strategic Commissioning)
 - Personalisation and Outcomes Checkpoint Group
 - NHS Lothian Self Directed Support (SDS) Steering Group



Florence Garabedian, Chief Executive Officer

In addition, we have worked collaboratively on projects with the following organisations:

The Edinburgh Development Group (EDG), Action Group, People First Carers of West Lothian, VOCAL, Capability Scotland, ENABLE Scotland, The Thistle Foundation, Contact a Family, Penumbra, MECOPP, Butterfly Trust, CCPS, LGBT Youth Scotland and Social Work Children and Families Teams.

Activities undertaken in partnership have ranged from promotional activities, attending groups to implement changes around Self-Directed Support to consultation events, our training programmes and setting up referral processes with other organisations.

Policy and responses to consultations

Throughout the course of the year we provided a number of responses to local and national consultations to ensure disabled people's views were taking into account in the development of policy. LCiL is able to engage positively on national issues such as the welfare reforms, Self-Directed Support legislation and currently the integration of health of social care. A full list of our consultation responses can be found on our website: www.lothiancil.org.uk



Our input into policy development has also included supporting disabled people to speak at committees and events on behalf of other disabled people about their experiences.

Building the foundations for intensive work on Self-**Directed Support developments** in the Lothians



In December 2011 we eventually secured funding (see accounts) over 2012-2015 from the Scottish Government to run a 3 year Self Directed Support (SDS) Development Programme. This will enhance our capacity to respond proactively and effectively to the changes, challenges and opportunities brought by the SDS Bill and the SDS strategies.

LCiL also secured funding from the Innovation Fund and from the Enterprise Growth Fund which have consolidated LCiL's financial position for 2011-12 and will continue to do so in 2012-13. Our full accounts can be read on page 18.

Read on to see our key developments within each service over the course of 2011-2012...



Key services over the year

Across LCiL we have a number of services which aim to enhance the independence of disabled people. Here we highlight key facts of each service over 2011-2012.



Our payroll service processes payments of Personal Assistants (PAs), which takes the burden off disabled people by dealing with the PA timesheets, tax, national insurance and many other related important administration issues.

Key facts

- > During the year the demand for the payroll service grew by 10%
- > A total of 349 disabled employers made use of our payroll service
- > On average 763 salaries were processed each month for PAs - this is nearly 10, 000 salaries over the course of the whole year.
- > Regional breakdown and numbers of Service Users:

Edinburgh	196
Midlothian	45
East Lothian	38
West Lothian	67
Private	3

New initiative: Enhanced financial management support

> Identified need

Many disabled people choose to employ their own PAs because it gives them more choice and flexibility around when, where and how support is provided to them. For some people, and for different reasons, managing the financial aspects of a support package is not an easy task.

Payroll provides a comprehensive, payroll service for PA employers which also provides a link with the Inland Revenue and operates on a helpline basis for disabled employers. For more information contact 0131 475 2350 or email: payroll@lothiancil.org.uk

Also, in 2011 the Inland Revenue announced they were closing a simplified payment scheme, which left many who employed their own PAs facing an unfamiliar and complex system different from what they had been used to before.

> How it works

Our Payroll service holds and operates a 'client bank account' on behalf of a service user in receipt of a direct payment. The service can then help make payments for chosen purchases (e.g. a direct care provider, an agency or personal assistants). It also administers other funds received to pay for care and support.



The service can be tailored to suit individual's circumstances and enables people with less capacity to access and benefit from a flexible support without struggling over how they manage this.

> Difference made

Here an anonymous service user speaks about her experience of using the service: "The enhanced service came in the nick of time for me. It takes from me most of the paperwork and the burden of dealing with Inland Revenue,



and gives me the confidence that I can continue to employ direct staff whom I have personally selected, to give me the degree of help I think I need, at times to suit me. Without it, I would probably have to fall back on agency staff, with little control over who comes or when they come, or what they are prepared to do when they come.

It is not an exaggeration to say that the enhanced service has helped to preserve my quality of life!"

'The service can be tailored to suit individual's circumstances and enables people with less capacity to access and benefit from a flexible support without struggling over how they manage this.'



ILS provides a support service for people considering setting up and managing their own independent living packages. The service provides support so people can take up Self-Directed Support and direct payments. This includes helping disabled people to employ their own Personal Asistants. Support is also provided on an ongoing basis as required e.g. through peer support groups (see article below)

Key facts

- > Through 2011-2012 ILS supported a total of 297 service users
- > 125 new referrals on average 30 new service users each quarter
- Regional

breakdown	Existing	New
Midlothian	25	7
West Lothian	83	34
East Lothian	36	21
City of Edinburgh	1	
Council	153	63
TOTAL	297	125

Focus - Working with others

ILS worked with a number of organisations in different ways including promoting Independent Living and take up of direct payments amongst disabled people and people with long term conditions across Lothian. This has included involvement in an NHS Direct Payment pilot, taking part in a film for City of Edinburgh Council's DVD to tell others how DPs have made a difference in the lives of disabled people.

ILS have also targeted groups where take up of direct payments have been traditionally low, including young people in transition (through Future Fairs Event in East Lothian) and ethnic minorities (through talks to Multicultural Family Base, Ethnic Minority Law Centre, and the Minority **Ethnic Health Inclusion Service** (MEHIP).

ILS and Peer Support

Katrina Sweeney, one of LCiL's Independent Living Officers talks about the Peer Support Group in 2011-2012:

What is the peer support group?

The peer support group is for disabled people who employ their own PAs. It provides a safe space to discuss and share experiences of being an employer.

How long has it been around for?

The Lothian wide Peer Support Group has been meeting for around 15 years in Edinburgh. It was started because disabled people wanted to come together and talk openly about employing PAs.

How has it made a difference?

The group, whilst primarily supportive in their role as PA employers, has also enabled participants to find out and explore other issues affecting disabled people, including:

- Direct Payment packages under review and threatened removal of DPs
- Implications of PVG Scheme
- Impact of welfare reforms
- Liaising with local authority departments and other appropriate organisations
- Assisting with set up and delivery of enhanced support service
- LCiL training programmes.



Katrina Sweeney **Independent Living Officer**

What are your hopes for the future?

For disabled people to continue recognising the benefit of sharing their experiences with others. The peer support group has been so successful in Edinburgh that there is now a wellestablished local peer support group in East Lothian.

For more information on the peer support group or any other aspects of Independent Living Support contact LCiL on 0131 475 2350 or email: ilt@lothiancil.org.uk

'For disabled people to continue recognising the benefit of sharing their experiences with others. The peer support group has been so successful in Edinburgh that there is now a well-established local peer support group in East Lothian.'



LCiL service: Grapevine

Grapevine – the Lothian disability information service provides up-to-date, reliable and accessible information for disabled people and their supporters in Edinburgh, East Lothian and Midlothian.

Key facts

- Responded to 2195 enquiries for advice and information from 1079 individuals and organisations in Edinburgh, East Lothian and Midlothian.
- > Who contacted the service?

 Disabled People 	553
 Family/Friends 	162
 Voluntary Organisations 	184
 Local Authority workers 	73
 Health service 	25
 Other (e.g. volunteers) 	82
Total:	1079

Method:

• Letter

 Phone calls 	538
 Online (including email) 	184
 Face to face interviews 	85
• Talks	230
(enquiries via 48 talks)	

Over 2,500 copies of the quarterly disability information newsletter 'Lothian Disability News' were distributed.

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- In January 2012 a List of Care Agencies in Lothian was updated.
- > Grapevine continues to provide up to date news and information on the LCIL website.

> Subject of Enquiry

Judgeet of Enquiry	
 Financial: (including grants 	
and trusts)	598
Benefits Advice (including	
Disability Living Allowance	
forms)	808
 Care and Support (including 	000
direct payments)	182
 Access (including transport, 	
equipment, housing)	260
 Education & Employment 	51
 Holidays Leisure 	45
• Legal	70
 Personal Health 	30
• Voluntary Organisation referral	36
• Grapevine leaflets, publications	37
 Other LCiL services 	72
• Misc:	10

'In the last year the number of enquiries from disabled people wanting information about benefits has risen by 34%.'

New focus on welfare reforms: keeping abreast of the changes

Identified need

In the last year the number of enquiries from disabled people wanting information about benefits has risen by 34%. This includes a 16% increase in support with applications for Disability Living Allowance (DLA) and 28% rise in enquiries regarding other benefits such as Employment Support Allowance (ESA). It is likely that this will increase as welfare reforms are implemented over the coming years.

What happened?

In partnership with City of Edinburgh Council Grapevine delivered talks to disabled people in four of the City's Edinburgh Neighbourhood Partnership (NP) areas, on the changes being proposed to disability benefits, under the Welfare Reform Bill.

Making a difference

As a result of the talks many were able to contact Grapevine for individual advice and assistance, including assistance to fill in DLA and Attendance Allowance (AA) forms. Grapevine also produced a welfare reforms briefing paper reflecting the views and concerns of disabled people which was sent to all members of the Scottish Parliament (MSPs) and local elected members in February 2011.

This has made an impact at two levels. Grapevine has paved the way for closer links to be made with disabled people in the community, including other groups such as older people, people with mental health issues and people with progressive neurological conditions. It has also given them recognition at a wider level, with commissioners of services and politicians taking note of the issues disabled people are raising with the information service. Grapevine continues to provide up to date announcements in Lothian Disability News and other outlets such as talks and the LCiL website.



LCiL service: Training

LCiL's training service creates learning opportunities for disabled people to develop their skills and also offers competitively priced training for organisations on topics such as Disability Equality and Direct Payments.

Key facts

Training Service

Delivered 11 training courses over 27 days with 81 participants including:

- > Two Training for Personal Assistants (T4PAs) courses
- > The second session of 'Your Time to Choose' course, providing information on Self-Directed Support to young disabled people, with funding from Ponton Trust.
- A further successful funding from Ponton Trust also enabled us to deliver Training for Personal

Assistants to young people under the age of 29.

- Continuation of the Elementary Food & Health REHIS (Royal Environmental Health Institute of Scotland) course, funded by Community and Food Health (Scotland).
- > Fife Council commissioned a one to one training on employer skills
- > 24 participants from Access Panels across Scotland took part in commissioned training on Disability Equality.

LCiL's Training Resource Pack, a national resource available to Disabled People Organisations across Scotland, was also updated to incorporate legal changes (arising from, the introduction of PVG Scheme in Scotland and the new Equality Act 2010).

Focus on financially sustainable training

Identified need

In times of severe budgetary constraints it becomes more challenging to cover costs of training courses to ensure those most in need can access skills



and knowledge. The training service developed a plan to roll out a pilot scheme to enable participants to obtain Individual Learning Accounts (ILA) to fund places on the T4PAs courses.

How it works

A successful partnership was developed with an ILA Scotland registered agency, Mi-Tech, to enable people with ILA accounts to register on the T4PAs course as a pilot initially. The course was registered and promoted through ILA Scotland and proved to be hugely successful, with the number of requests exceeding the number of places available.

Making a difference

The T4PA course through the ILA scheme has opened up training opportunities to many more individuals who may have not taken them up otherwise. Some participants had English as a second language and wanted to gain knowledge to improve their employability skills. The courses have been made up of mixed ages which worked well with the differing experiences.

"I would like to see more of these types of opportunities as everyone seems to have so much to discuss and so much to learn."



Amanda Beech LCiL's Training Officer

Comments included:

"I'm more knowledgeable now about barriers disabled people face and access."

"I would like to see more of these types of opportunities as everyone seems to have so much to discuss and so much to learn."

"I gathered a lot of information and was very happy to attend such an informative session."

Lessons learned

Over the next year, the Training Service will focus on developing this strategy to obtain ILA accreditation for other courses, whilst simultaneously encouraging disabled people to access ILA. This will enable disabled people not only to use their ILA to access the LCiL courses but also to participate in other educational and leisure courses registered with ILA Scotland.



Your Call is a national counselling service for disabled people across Scotland. Provided by trained counsellors who are themselves disabled, it offers free and confidential counselling via telephone and email.

Key facts

- > During 2011-2012 the service provided: 664 counselling appointments of 1 hour each, amongst 53 clients from across Scotland.
- > Regional breakdown: **Edinburgh and Lothian** 21 **Greater Glasgow** 12 Grampian 8 12 Other parts of Scotland > Condition/disability Physical impairment 33 Mental health issue 9 Learning difficulties Other (e.g. long term condition) 7
- > Referrals came through a variety of sources including NHS, local authorities (e.g. Shetland Islands Council), local counselling organisations and voluntary agencies work such as Epilepsy Scotland, Health in Mind, RNIB, Capability Scotland and Into Work.

Focus on success: Your Call wins 'Self **Management Project** of the Year'

Identified need

In October 2011 Your Call was awarded 'Self-Management Project of the Year' by a national alliance set up for people with long term conditions (LTCAS, now The Health and Social Care ALLIANCE). The award was presented to them following Your Call's work on self-management via two ways. Firstly by working with people with long-term conditions from all over the country and increasing their capacity to selfmanage through providing counselling. Secondly by hosting the 'Moving On' Conference with over 120 delegates from across Scotland.

Making an impact

As a result of using the Your Call service seventy per cent of clients have reported making positive changes in their lives. For example nearly half of clients who took part in a client survey in 2011 reported reduced visits to their GP, which is indicative of reduced use of NHS resources.

These ideas were explored further during the Your Call conference called 'Moving On' which brought together people from a wide range of professional backgrounds. The event provided an opportunity to discuss psychological and emotional support for disabled people and people with long term

conditions in Scotland and promote non-medical approaches to supporting self-management.



Your Call Counsellors and staff.

Speaking from experience

Your Call has demonstrated the effectiveness of counselling based approaches in supporting people to selfmanage, whilst increase understanding amongst individuals, voluntary organisations, statutory sector and other practitioners of its value.

'As a result of using the service seventy per cent of clients have reported making positive changes in their lives as a result of counselling with Your Call.'

These are reflected in these quotes: From a Your Call client

"By talking things through in a calm, rational way, my anxieties dissipated quite a lot ...talking is by far the best medicine and I am eternally grateful for the support I have been given...it's brought about a reduction in visits to my GPs."

From a Scottish Government **Medical Advisor attending** the 'Moving On' Conference

"I was immediately impressed by the emphasis away from drug treatment towards psychological support for emotional wellbeing. The further emphasis on the context within which people who are disabled find they are further disabled emotionally e.g. social isolation was an important message."

Lothian Centre for Inclusive Living Income and Expenditure Account



to year ended 31 March 2012		
	2012	2011
	Total	Total
INCOMING RESOURCES	£	£
Incoming resources from generated funds		
Voluntary Income	579,792	534,900
Investment Income	543	1,521
	0.0	.,=.
Incoming resources from charitable activities	176,338	174,989
Other incoming resources		
Pension finance income	16,000	9,000
Total incoming resources	772,673	720,410
RESOURCES EXPENDED		
Costs of generating voluntary income	20,737	16,019
Charitable activities	566,115	565,416
Governance costs	7,149	7,541
Total resources expended	594,001	588,976
Total resources expended	394,001	300,970
NET INCOME (EXPENDITURE) FOR YEAR	178,672	131,434
OTHER RECOGNISED GAINS/LOSSES		
Actuarial gains/losses on defined		
benefit scheme	167,000	81,000
Net movement in funds	345,672	212,434
Total funds brought forward	374,439	162,005
Total funds carried forward	720,111	374,439

Full copies of audited accounts available on request.

To the future...

Over 2011-12 LCiL has evolved and we will continue to respond creatively to changes in welfare and social care. As our services develop to meet the challenges and opportunities these changes bring we will measure the impact our support has on people's lives. We will use this information to constantly develop and improve so that we can continue to offer the best possible support to service users to achieve the choice and control they want in their lives.

Over the coming years we will continue to implement out strategy and our 3-year Self-Directed Support Development Programme. We will also actively seek sustainable funding for all our services, while continuing to deliver the support which Members and service users have identified a need for.



Who is Who at LCiL?

Directors and Officers

Convener

Jeff Adamson

Other Directors

Liz Pearston

Pamela Judson – resigned May 12

Louise Doctor

Jimmy McIntosh - resigned January 12

Colin Cameron
Ann Robertson

Dugald McArthur - resigned May 12

Suselle Boffey

Chief Executive

Florence Garabedian

Treasurer

Liz Pearson

Registered Office

Norton Park Centre

57 Albion Road, Edinburgh EH7 5QY

Auditors

Brown, Scott & Main 91 West Savile Terrace

Edinburgh EH9 3DP

Bankers

Clydesdale Bank PLC, Edinburgh

Co-operative Bank, Manchester

Company Number

SC129392

Charity Number

SC017954

Staff

Chief Executive

Florence Garabedian

Operations Co-ordinator

Sandra Main

Fundraising Co-ordinator

Hazel Farley

SDS Development Officer

Debbie Bayne

Administrator

Carol A Kelly

Independent Living & Training

Co-ordinator

Louise McMeel

Independent Living Officers

Katrina Sweeney, Kirstie Ogilvie,

Srabasti Dhar, William Neil,

Omar Haq

Payroll Co-ordinator

Alison Walsh

Payroll Officers

Stephen Lane, Lorraine McKay,

Ruth Currie

Information & Communication

Co-ordinator

Kirstie Henderson

Information Officer

Andy Groves

Your Call Counselling Co-ordinator

lan Fuller

Your Call Administrator

Kelly Jack

Training Manager

Sunil Bhatnagar

Training Officer

Amanda Beech

Project Administrator

David Fulton

Also: Maggie Cameron continued to be seconded to Self Directed Support Scotland (SDSS) and

left LCiL in May 2012. Catherine

Garrod left her post as Information Coordinator in March 2012.