

Lothian Centre for Inclusive Living

Independent Impact

An external report on LCiL's impact,
values and services



www.lothiancil.org.uk

Lothian Centre for Inclusive Living (LCiL)

Independent Impact

An external report on LCiL's impact, values and services

by Graeme Reekie MBA CMGr FCMI, Wren and Greyhound Limited, June 2018

Contents

About the report	1
1. About LCiL	2
2. What makes LCiL different?	4
3. LCiL's impact	7
4. LCiL's values	19
5. LCiL's services	28
6. Future wishes	35

Note on language

This report uses the word '**people**' rather than 'service users' or 'disabled people' wherever possible to avoid the limits that labels impose. People who took part in interviews have a large variety of connections with the organisation.

Finding your way through the report

This is a digital version which combines written text and video clips. You will find a number of quotes from people who do not appear on the clips. In addition, if you click on a face with a green-white arrow at the centre, you will be redirected to **YouTube** and can access each clip directly.



“LCiL is a professional organisation with boundaries and standards in place but with a very human, genuinely person-centred approach”

About the report

“I hope that this report will open the minds of people reading it, in the sense that it will bring a bit of space for them to think there may be other ways of supporting, enabling and building the capacity of people. It is how we do it together, LCIl colleagues, people we work with, partner organisations, all of us” Florence Garabedian, Chief Executive, LCIl



This is an independent review of **Lothian Centre for Inclusive Living (LCiL)** and its impact. It took place in May 2018 and drew on evidence from a range of sources – see below. Interviews and focus groups with 15 service users, 2 carers, 4 staff and 10 external partners provided a rounded picture of LCIl’s value. These interviewees were selected to give a representative view of LCIl’s different services. Once the evidence had been gathered, the external evaluator facilitated a focus group to verify and shape the content.



Sources of evidence used

1. About LCiL

Lothian Centre for Inclusive Living (LCiL) is a user-controlled organisation which supports around 1,500 disabled people, people with long-term conditions and older people, to live independently in their communities.

Its services are described more fully in Section 5 (page 28) but include:



▲ Providing information and one-to-one support to manage self-directed support packages.



▲ Processing wages and administration for people employing Personal Assistants.



▲ Free, confidential, independent disability information and advice for people in Edinburgh.



▲ Workshops, peer support groups and one-to-one peer support to help increase knowledge, skills, confidence and resilience.



▲ A group of service users who are trained and supported to share their lived experience of independent living, self-directed support, LCiL services and peer support.



▲ Training for individuals and organisations on topics such as disability equality and self-directed support.

95% of the 231 service users who took part in the 2018 service user survey would recommend it to others.

Similarly, all 15 people we interviewed value LCIl highly, describing it as unique, positive, hopeful and solution-focused. Two people reported a time when the organisation didn't get things right, but LCIl responded quickly and sensitively to resolve the issue.

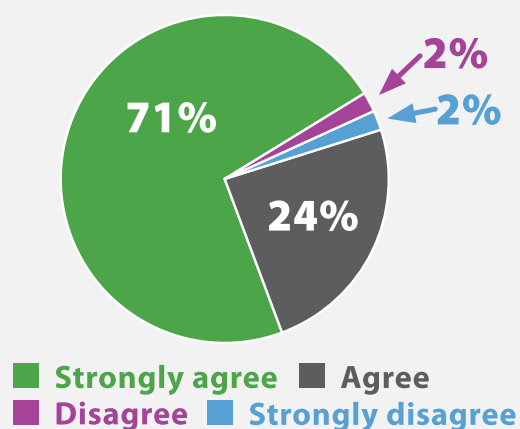
“When somebody gives you a glimmer of hope about one thing, on one day, that changes the rest of that day and reminds you that you will find a way through” Naomi

“They always build up on previous, positive experience that you have had with them” Lia

“It is unique in the way that it supports people to live independently without being a support agency” Ashleigh

“Of all the services that we use, LCIl is very much at the top of the go-to list. They come with a package of empathy, understanding, time and patience. When it comes to assessments and knowing rights, there is nobody else that knows that rounded information as well as LCIl. Working with LCIl helps me stay professional – because of the confidence and trust, I know what to expect should I refer somebody. It is that extra mile that they go – they do much more than it says on the tin” A referrer's view

“I value the work of LCIl and would recommend the organisation to others”



“Working with LCIl helps me stay professional – because of the confidence and trust, I know what to expect should I refer somebody” referrer's view

2. What makes LCiL different?

In addition to the values identified in **Section 4** (page 19), there are **six factors** that make LCiL special in the view of services users, carers and external partners:

- ▶ It is a disabled people's organisation run by and for disabled people.
- ▶ Its breadth of expertise – disability-specific, not condition-specific.
- ▶ Knowledge and understanding of what matters.
- ▶ It is a 'one-stop shop'.
- ▶ Consistency and integrity over time.
- ▶ Help is always there on the end of a phone.

▶ **Disabled people's organisation**

LCiL draws its identity and purpose from being a disabled people's organisation. When asked in interviews why this matters, people emphasised inclusiveness, commitment and empowerment.

“It is important that there is a majority of disabled people on the Board. There is an old cliché, nothing for us without us. Having lived experience, it is important that you have a voice of what is really happening and how things are working” Jeff, Trustee



“I knew where they were rooted, the disability rights basis. Coming here, I wasn't going to be met with anybody that was going to be patronising, it wasn't going to be condescending” Rohan

▶ **Breadth of expertise – disability-specific, not condition-specific**

Although people described valuing condition-specific services, they believe there is something special about LCiL's ability to welcome all disabled people.

“Because LCiL is not impairment-specific, it is about supporting each other and seeing what you need specifically, personally. There is too much emphasis within other organisations about 'you have to fit the box', and I very much believe there isn't a box, I don't fit a box, I'm star-shaped. Here it is OK that I am star-shaped, it doesn't matter, they will still find a way that you will be included, welcomed and part of whatever is going on” Naomi



► Knowledge and understanding

LCiL staff have valuable expertise in disability-related topics, but they don't pretend to be 'the experts'. Instead, they listen to understand, putting people at the centre of everything. Their empowering support, based on genuine acceptance, can be life-changing (see **Section 3** page 7).

“If I speak to an Independent Living Officer, I know that if he or she doesn't know a solution, they would ask someone else in the team, and I know there is so much knowledge and expertise available there. That is unique” Jeff

“They were very friendly, very patient. They had a lot of questions that nobody had asked me before, so it showed a genuine interest in what was happening to me. I was treated as a person, as an individual. It was very person-centred and positivity-centred, always focusing on giving hope and not taking hope away” Lia

“We have built up a relationship over time. We trust in their knowledge. They are expert in their way” Referral organisation

► One-stop shop

This was one of the most common responses to the interview question, "What makes LCIl different?" In the 2018 service user survey, 94% also said LCIl should remain a one-stop shop.



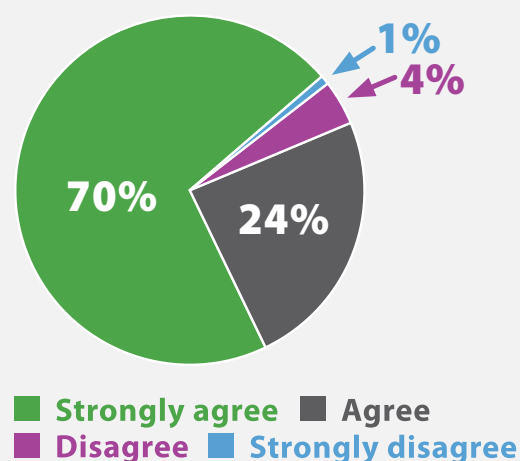
“It is quite a broad brushstrokes organisation. A lot of other organisations are just as good and just as important in more specific areas, but LCIl covers the length and breadth” Dugald, Trustee

Although LCIl have many services under one roof, they realise the limits of their expertise and refer to other organisations when appropriate.

“They are really effective when it comes to having to pass your enquiry on to another group. They have also done inter-agency referrals for me, when my need was something that they couldn't cover” Lia

“That directness is about being open, saying these are the options and this is definitely what we can support you with, but this I will have to go and ask someone else about or refer you” Partner organisation

“It is important to me that LCIl remains a one-stop shop”



► Consistency and integrity over time

LCiL supports **independence** and **empowerment**, but that doesn't mean closing the door behind people once they have what they need. Service users, most of whom have lifelong disabilities, value continuity, knowing they don't need to re-tell their story every time they need more help or information. And referrers appreciate that LCiL staff build up understanding about their service users over time.

“They have continuity, once they take you on board, you are always in touch with them. Time-limited services can help with certain issues, but continuity to me is hope” Lia

“In a world where everything is always closing down because of funding, everything is having to manoeuvre and change, you need a service that really understands you and has disabled people at the heart of it” Kirin

“One of the advantages of having the consistency of someone like [LCiL staff] coming is that they understand the impairments that that person has. In that way, they have become very much part of the team and have absorbed a lot of information that is condition-related” Partner organisation



► Help is always there on the end of a phone

In the same way that it matters to have continuity, people frequently described the reassurance that comes from having ‘an ally at the end of a phone’. In the 2018 service user survey, 96% of people reported that this is important.

“The comfort blanket. You know that if anything goes wrong, there is someone at the end of the phone that can help you resolve the issue” Jeff

“Just to know that they are there makes me a lot more conscious and a lot more courageous” Lia

“My hand was held throughout the entire process. Constant reassurance and the fact that the member of Independent Living Team was always available to me, via phone or email” Parent carer



3. LCiL's impact

LCiL has adopted one overarching aim: enabling people to achieve their personal outcomes and the life they want to live. This is supported by **four outcomes**:

- ▶ People are more aware of the support available to access and manage Self-Directed Support.
- ▶ People make more informed choices or have the information to navigate the system.
- ▶ People have gained/increased confidence.
- ▶ People have maximised opportunities for choice and control.

It should be noted that the impact review did not go looking for evidence of these outcomes. Instead, it asked open questions about the difference LCiL makes to people and encouraged stories to emerge in people's own words. As a result, the answers people gave provide good evidence for each outcome (see the table on pages 8-9), but nine 'added value' outcomes also emerged. These are things LCiL did not explicitly set out to achieve but which were well evidenced in interviews. Some of these are arguably more significant than the current organisational outcomes.

LCiL may therefore want to review its outcomes so its full impact can continue to be measured and celebrated in future.

As well as each of the outcomes being fully explored and illustrated below, people also gave powerful examples of what their lives might have been like without LCiL.

“If I hadn't been introduced to LCiL I don't know where I would have been. Possibly in residential care. I don't know if my marriage would have survived, because of the stress and pressure for my wife of being a full-time sole carer. I think I would be isolated. I wouldn't have had the contact with other disabled people that I have now, or the understanding of what life could be – the positive aspects of being disabled” Jeff



► Overview of outcomes and findings

There is strong evidence that LCiL has exceeded its intended outcomes and achieved several more. The table here and the next page gives an overview, followed by full details from page 10.

LCiL aim: Enabling people to achieve their personal outcomes and the life they want to live (full details on page 10)

Added value outcomes	Summary of findings
Improved quality of life ►	People commonly reported reduced stress, improved wellbeing and sustained personal relationships. Several also described recovering purpose and identity after life-changing events.
Employability, volunteering and activism ►	Four interviewees found paid work as a result of skills and confidence gained at LCiL. Four more found voluntary roles. All eight work in support, policy or training roles in disability-related issues.
Less isolated, more connected ►	People developed positive, supportive relationships with peers. LCiL is described as welcoming, creating belonging and ownership. These are good indicators of sustainable impact.

LCiL outcome 1: People are more aware of the support available to access and manage Self-Directed Support

(full details on page 13)

Better supported, acknowledged and understood ►	LCiL centres on the whole person, not problems, providing non-judgmental acceptance. This enables people to accept support. This contrasts with the 'guilt' felt when using (or being assessed for) other support, though this changes when people learn about their rights and the social model of disability.
--	---

► **Overview of outcomes and findings** continued**LCiL outcome 2: People make more informed choices or have the information to navigate the system** (full details on page 14)

Added value outcomes	Summary of findings
Better informed ►	All of LCI's services provide expert information, raising awareness of rights in empowering ways. In training and peer support, this was described as 'eye opening' and 'life changing'.
Increased awareness and fulfilment of rights ►	LCiL increases people's awareness of, and ability to achieve, their rights. Interviewees stressed the realistic and empowering ways LCI works, agreeing mutual roles and expectations.

LCiL outcome 3: People have gained/increased confidence (full details on page 15)

Increased self-belief and self-worth ►	In interviews, this was the most evident of all the outcomes, with 10 out of 15 people emphasising the confidence, courage and self-worth they found at LCI.
--	--

LCiL outcome 4: People have maximised opportunities for choice and control (full details on page 17)

People have increased choice and control in their lives ►	This outcome is the culmination of the other three. Common examples included being better listened to by other agencies, and having more control over personal care and personal budgets. Two people also cited the savings they have made to public funds by controlling their own SDS budget.
Increased independence ►	Independent living was of major importance to interviewees. Loaded with meaning, it describes people's ability to live their own lives, with autonomy and support. Four people described being able to live in their own home (two following 'seamless' transitions from long-stay hospital care) thanks to LCI's input.

LCiL overall aim: Enabling people to achieve their personal outcomes and the life they want to live

Unsurprisingly for a person-centred organisation, LCiL has a person-centred aim, choosing not to define or limit the things it can help people to achieve. Nevertheless, people did describe their outcomes and achievements at LCiL, and these are explored below.

First, it is important to understand what 'enabling' means. The word is often used without real meaning – but it means everything to people at LCiL.

“Enabling means that you allow somebody to do something on their terms. Enabling is supporting and allowing someone to be able to make choices. In a world where choices are quite often limited for disabled people, that is really important. Choices on your level, on what you want – and on an equal basis”
Kirin

The outcomes and lives that people described in the review can be grouped into three areas of impact:

- ▶ **Quality of life** (pages 10-11)
- ▶ **Employment, volunteering and activism** (page 12)
- ▶ **Reduced isolation and increased involvement** (page 12)

Each of these areas are explained below using people's own words:

▶ **Quality of life**

“When I came here first, I was alone, unsupported and marginalised, disabled, immigrant, female, domestic abuse survivor – I was the case study of disadvantaged people in society! Now I am a paid advisor for a prominent organisation, I am a very successful volunteer, I have my beautiful fiancé, I don't have this fear or guilt to speak about what I need any more. I am a very different person” Lia



“LCiL is very human. It's not like any other organisation. I think people actually speak to you, they look at you rather than worrying about what you can't do, they focus on what you can do. It is very caring, positive. That is something I try and translate into my work” Omar

A parent's story

A huge difference

“We have total confidence when my son and his PA leave the house together and set off on one of their Saturday morning adventures, that she will take very good care of him, and respond to him, and engage him in a way that is appropriate, and that he will have fun with her. It has made a huge difference to us. We can send him out without any stress. Then we have those few hours for ourselves or for spending with our other son, and that is hugely valuable. The change is really striking. Respite is supposed to be stress-free and it just wasn't when we were accessing another service. LCiL has made that happen for us and it is massive to us. It wouldn't have happened without the support we have received, we would still be with the previous charity and feeling frustrated and angry that the council was paying for an expensive service that doesn't provide what it is supposed to provide. Employing a PA directly costs half as much as accessing respite through the previous service”

Helen's story

It has been a lifeline

“At the beginning, I used to think, I don't need this support. It was completely new and it was foreign to me. In reality, it has allowed my partner to be able to go out and do things, she doesn't have to be stuck here. We have got two adopted children, they are grown up now, but one of them still stays with us and he has got quite complex needs. We had never had respite before. Being able to go away for 24 hours, that is just wonderful. That's made an incredible difference. The other thing is the security and safety for the family that somebody's with me when I'm out and about. It has been a lifeline. As time has gone on, I have come to realise that I do need it”

► Employment, volunteering and activism

First, it is important to understand what 'enabling' means. The word is often used without real meaning – but it means everything to people at LCIl.

“I got involved with other disability organisations. I became a member of the Independent Living in Scotland Steering Group. I am part of the physical disability planning group on Midlothian Council.

I'm now chair of the Scotland Against the Care Tax campaign, so I am meeting other people from different organisations throughout Scotland through that, and I am also getting involved in the political aspects of the way politics runs” Jeff



“I am happier. I am active and getting involved in the community. I am now holding down two jobs, which I couldn't do without my support. One is a trainer, which I really enjoy. I couldn't have done that without the training that I got at LCIl” Caroline

“I am happier. I am active and getting involved in the community. I am now holding down two jobs, which I couldn't do without my support”

► Reduced isolation, increased involvement

People consistently describe LCIl as welcoming. Relationships between staff, volunteers and services users are based on accepting and valuing people. This creates a sense of belonging – and ownership. It was not unusual for service users to use the word 'we' (rather than 'they') when talking about LCIl. This sense of ownership fosters natural, supportive connections in people's lives and communities – a good measure of sustainable impact.



“They have given me chances to do things I didn't think I'd be able to do. They have allowed me to make friends. They have broken down my isolation” Kirin

LCiL Outcome 1: People are more aware of the support available to access and manage Self-Directed Support

The **2018 service user survey** shows that this outcome is achieved for the majority of people using LCiL services:

- 90% of people reported knowing what is available to help manage their support
- 88% reported increased knowledge of Self-Directed Support

In interviews and focus groups, people gave examples of this outcome being achieved, but they also described feeling more **acknowledged** and **understood** by LCiL. This understanding leads to enablement and empowerment.

“I had a review with the social worker and was able to say that the current system wasn't working for us, and what we would like to do is start directly employing somebody ourselves. Prior to that, I had been in contact with a member of the Independent Living Team and had talked through how we would go about doing that. Just having that support gave me the confidence that I needed to embark on the process” Sinead



“Once LCiL got involved and I got my Independent Living Officer, and people started to pay attention to my assessment and giving me material to prepare for it, everything changed and within a couple of months I was equipped with a care package and a PA” Lia

LCiL outcome 1: Added value outcome

► Better supported, acknowledged and understood

LCiL's support was described as human, empathetic and respectful. People experience this as enabling and empowering. It provides space for people to be themselves without fitting into boxes.

“A lot of organisations really made me feel like just a client. LCiL have always made me feel very equal with everyone else. Respectful, keeping your dignity, they show respect towards you every time you talk, and that is really important” Lia

“For me, I was struggling and they got it right in terms of that – it wasn't sympathy, it really was understanding of impact” Rohan



LCiL Outcome 2: People make more informed choices or have the information to navigate the system

This outcome was very well evidenced in the impact review by people making choices and exercising their rights in all areas of life. It is explored in two parts below. Firstly, people describe being better informed as a result of LCIl's input, and secondly, they believe in their rights as disabled people and citizens (i.e. not just their rights to access systems and services).

Added value outcome ► Better informed

“If you are going to become an employer, then you're going to have to know your rights and responsibilities, consider things like advertising, what to advertise, job descriptions, timetabling – none of these things had occurred to me. The LCIl worker went through it with me again and again, drawing up the frameworks for job descriptions and adverts” Dugald



“We make sure that people have information and advice that is relevant to their needs at the right point in time, the right place and in the right format. We will take time with people and talk through to explain what their rights and choices are, and make sure that they understand, and enable them as much as possible to make choices based on their own needs and circumstances” Kirstie, staff member

Added value outcome ► Increased awareness and fulfilment of rights

Taking a rights-based approach is one of the key aspects of LCIl's work (see **Section 4**, pages 24-25). It is also embodied by service-users, who all spoke with confidence about their identity and rights as disabled people.



“The support of LCIl has enabled me to be a proud disabled person that sees it as a right to live independently, and knows that I am entitled to the support that I get, and to have been able to go on and achieve what I have done. Had it not been for LCIl, I don't think I would have seen it as my right to live independently” Nathan

LCiL Outcome 3: People have gained/increased confidence

“ The workshops helped with getting confidence from other people ” Jeff



Added value outcome ► Increased self-belief and self-worth

“ LCIl has given me my confidence back. I believe I can do things and they believe in me, and that is massive. They have made that difference. They have made me want to do things and they have made me come alive again - that is the absolute right description ” Kirin

“ LCIl workshops made me change the way I looked at myself on the inside, and it made me not care about what anyone else thought about when they looked at me, because that's their problem not mine ” Martin

“ They pay a lot of emphasis on pumping up your self-esteem. They equip you with the right skills and give you a voice ” Lia



Martin's story

Life-changing confidence

“I got involved with LCiL about two years ago. Before I came here, I spent a lot of time in my house by myself and I wasn't really doing much with my life. Coming down to LCiL was the first time in many years that I had actually left the house, never mind going to meet new people.



I was a bit apprehensive about coming at first. After attending the courses and a few of the peer support groups, being around other people with different disabilities – it's like when, if you are in a peer support group and you are telling one of your problems, you can automatically look and see in another person's face that they can relate to your situation, even if it's not exact. That makes you feel far more comfortable in yourself, and it makes you open up much easier.

It gave me a lot of confidence to change a lot of things in my life. I started attending the peer support groups once a month, and then I was given the opportunity to train as a one-to-one peer support officer for LCiL, which I completed. I felt good about myself for the first time in my life because I was using the lived experience of my accident to help others.

Since I started coming to LCiL, I have used the Independent Living Team and they have helped me recruit my own PAs. With LCiL giving me confidence, it made me decide to look at my finances and see if I could use them any better to get better support. I arranged a meeting with the Local Authority and also with the Independent Living Fund Scotland. After a successful review, I got my local authority to take over all my personal care hours and that freed up my ILF money for me to be able to take on PAs.

With the help of the payroll service at LCiL, I now recruit PAs and I'm out practically every day of the week. I attend the gym, I can go to my appointments without roping in my family and friends. Now I am volunteering for two different charities, I also work as a befriender, and I wouldn't have been able to do that if I hadn't got the confidence from the peer support groups that I attended at LCiL. I am also working as an external champion for LCiL, and I work as a one-to-one peer support worker.

My message would be, if you are sitting thinking that's your life, it's not – there is so much support out there that you can get. I would highly recommend getting in contact with LCiL. In the short time that I have been with LCiL, I've gone from being a recluse in my house – to now, where I can't see the end of where I can go, all I can see is going forward. I would recommend LCiL to anyone, because look how far I've come in eighteen months ”

LCiL Outcome 4: People have maximised opportunities for choice and control

Like Outcomes 1 and 2, LCiL's impact goes beyond this intended outcome. People don't just have more opportunities for choice and control, it is evident that they have more choice and control in their lives. Even more importantly, they commonly report being more independent as a result.

The service user survey results confirm these conclusions:

- 92% of people report that LCiL has improved the choice and control they have in their lives.
- 90% of people report that as a result of LCiL's support, they have been able to do other things that are important to them.

The importance of these achievements cannot be overstated, as disabled people typically have significantly less choice, control and independence than other people do.

Added value outcome ► People have increased choice and control in their lives

“When you are here, and you are treated like a human being and people are giving you suggestions and advice and signposting to where to get the right support for you – it does change your life. That sounds like a Hollywood line or from an advert, but it does. I am proof of that” Naomi



Added value outcome ► Increased independence

The quotes below help to illustrate what it means when people are supported to achieve independence in everyday living. (Independent living is explored more fully in **Section 4**, pages 20-22).

“LCiL's whole philosophy is about independence. They will ask if you need any adaptations, but they don't mollycoddle you. They are available to help you and they will ask appropriate questions, but they allow you the right kind and level of autonomy to actually lead your own life. I am very, very happy with that” Helen

“I can do so much more with my PA. I can go out to an art gallery if I want, have a cup of coffee. I've just had new floors put down in my house, which was major work and mum and dad didn't have to come across because we managed it between us” Caroline

“It just afforded me the ability to come out of hospital, live in a house on my own, be able to get up and go to bed when I wanted, go to the cinema, go and do anything I wanted, make my appointments, and begin steps on the way to me going back to work. I was able to do that from a comfortable, stable environment where I had the support to allow me to do that” Dugald

“LCiL has quite literally changed my life. It has allowed me to gain independence in terms of going to university, physical independence by having my PA, to move in to my own house and have independence that way. It has given me financial independence because I've had the job and been able to get a mortgage” Omar, staff member



“When things work really well for you as a disabled person, it's like what happens with everybody. You can get up in the morning, you can get dressed, you can go off to the shops when you like, you can eat what you want to, you can go to bed when you want to get into bed and you can actually go off and do work. You think, as a non-disabled person, “that's what I do all the time”, but as a disabled person, you are negotiating a world that isn't made for you” Kirin



4. LCiL's values

Although **Sections 2 and 3** above help to illustrate LCiL's uniqueness and the difference it makes, they do not fully adequately explain its full value. Other organisations could achieve similar outcomes in similar ways, but it is LCiL's values that really help to tell the whole story. This part of the report explores how LCiL lives its values – and how people experience them.

Four main values stood out in people's stories about LCiL's impact on their lives:

- ▶ Independent living
- ▶ Empowerment
- ▶ Rights
- ▶ Peer support

Each of these is illustrated below, introduced by quotes from focus group conversations. Focus group participants verified that these were the main 'themes' behind LCiL's work, and explained what they mean from a disabled person's perspective.

This is important, because the words might mean different things to different people: they might have technical definitions*, be misused – or mistakenly dismissed as jargon.

In fact, the review found that these values are at the heart of LCiL's work and aspirations. They are where its impact comes from. As with the outcomes above, it should be noted that the review did not set out to identify these values. They emerged from disabled people's stories and open questions about how LCiL works.

Two of the themes, independent living and rights, were identified above in relation to the impact LCiL has made. In this section, it is LCiL's approach to these rather than its impact that is explored.



* For example, a formally agreed definition of independent living, developed by disabled people, is available from [Independent Living in Scotland](#)

Values: Independent living

Focus group participants explain independent living:

- “Independent living is everyday life and relationships. Being able to enjoy the things others take for granted”
- “It’s good to live independently, it’s not healthy to be dependent”
- “Living equitably, on an equal basis as everyone else”
- “Having the support to live the life we choose. What I need for me”
- “Independent living helps us live in an inaccessible world”
- “Inclusiveness, valuing diversity, respect, choice and options”

One of the most striking things about the review was the unprompted way that almost all of the interviewees began talking about independent living. As noted above, this would not be expected if the term was just technical, or the language of professionals. It quickly became evident in interviews that the term and its meaning are fully owned by disabled people – and embodied by LCIl, as illustrated by this quote:

“Independent living means having the same choice, control, freedoms and dignity as non-disabled people. That sums it up. LCIl helped me to clearly see what it was, and now I have passed it on to other people” Jeff



“Having 25 hours a week when I can do what I want to get done, it’s made an amazing difference to my life. I go to the gym weekly to keep the muscles that I still use built up, so I am still able to keep transferring in and out of my bed. I attend all my appointments. I go to the football sometimes at the weekend. Now I am able to actually go out and meet friends as friends and not have to rely on them to have to take me home for a certain time at night. It gives me so much freedom in my life to pursue anything I want, because now is the only time since my accident, which has been 13 years, that I have actually been thinking about what’s out there and about what I can do, rather than sitting in my house thinking, is this it till I die? It’s not just the difference that it makes to your life, it’s the difference it makes to the way you feel about yourself and the way other people view you. That is my view of independent living, and I don’t see why everyone doesn’t have it” Martin

Nathan's story

The right to live independently

“I have been involved with LCiL for about 13 years. I first started to use the organisation when I started living on my own. As a disabled person, I knew that there was some support that I would need to enable me to live independently and have a good quality of life.

I had a social worker assigned to me and the social worker went through an assessment process and suggested that the best support for me would be getting direct payments. That is where the local council gives me money directly in to a bank account and it gives me the freedom to hire whoever I want to provide support for me.

That is where LCiL came in, because one of the services they provide is to support people who want to employ someone to help them. LCiL helped me with the process of recruiting a personal assistant, and they also carry out payroll services for me. My first introduction to them was when I was very first employing PAs and I really didn't know how to go about doing that. I got an awful lot of support from them in that original process. As someone new to employing a PA, it can be quite an overwhelming experience. All these years later, it is a very routine experience now that I go through when I am employing a new personal assistant.



“...everybody that works for the organisation is really committed to the ethos of empowering disabled people”

The most important thing to me in using LCiL is the fact that it's other disabled people usually that work for the organisation, and everybody that works for the organisation is really committed to the ethos of empowering disabled people to employ their own personal assistants, and giving people choice and control over their own lives. That is what is so important to me, compared to using an agency or a big corporate organisation. I don't think they have those values that LCiL have”

Nathan's story: The right to live independently continued

“Also, it is a really individual service. The staff that are working with you sit down and spend the time to look at what it is that you are looking for in a PA. I have always felt really confident and able to be really open with the staff here. I’m in a same-sex relationship and I’m trans. For me, having someone come in to my home and support me with intimate parts of my everyday life, it’s really important that the person I am employing is respectful of my identity and my relationship. Using LCiL gave me the confidence to say what it is that I am looking for in a person.

I think LCiL empower their service users through having a really firm ethos that comes through in everything that they do, that disabled people are treated as valuable members of society. It is clear that they see the right to independent living as a right, and that is what feels empowering. Some services could make it feel like they are doing you a favour by providing support to you, and as a disabled person, that is really disempowering – you don’t want to feel like someone is benevolently providing you with support, you want to feel that you are entitled to the support.

“The support of LCiL has enabled me to be a proud disabled person that sees it as a right to live independently”

LCiL really make the link between the support that you get provided with and then what that enables you to do. Through having personal assistants and having a lot of the stress and anxiety taken out of my life, I have been able to go to university, get a law degree, do a traineeship, get qualified as a lawyer, I’m about to start a job with the Scottish Government.

The support of LCiL has enabled me to be a proud disabled person that sees it as a right to live independently. I really don’t think I would have been able to achieve everything I have, had I not had the support that they have given me”

Values: Empowerment

Focus group participants explain empowerment:

- “ I don't need you to do it for me, I'll do it, but I need information ”
- “ Having a voice and having a say in society, and using it with diplomacy to get what you deserve, and not be seen as vulnerable or a nuisance ”
- “ LCiL do collective empowerment well. Having the voice that's more than one person standing up for a cross section of people. LCiL facilitate processes so we can use the power of our voice to do that well ”
- “ Truly empowered people empower others. It's a win-win ”

Disability and social care organisations describe themselves as 'enabling' and 'empowering' so often, that the words have lost some meaning over the years. They were therefore treated cautiously in the impact review, which sought to understand the reality behind the words. Three main strands stood out:

- ▶ People describe being better informed by LCiL. This means having good quality, reliable information, but also having realistic choices explained. (See Outcomes 1 and 2 on pages 13-14)
- ▶ This gives people more choice and control, and builds confidence to pursue different options. (See Outcomes 3 and 4 on pages 15-18)
- ▶ As a result, they are living more active and independent lives. (See Outcome 4 on pages 17-18)

“ After starting to work with LCiL, I realised that you are a soldier in this system, and you have to learn how to behave, how to conduct yourself, how to be assertive and what weapons you need. LCiL give a lot of support, but you have to develop the strengths ” Lia

“ You've got to find your own voice and take on the responsibility that comes with using it ” Focus group participant

“ People who have used LCiL are now supporting as volunteers. There is a pathway there, not just to empowering themselves, but they want to give back ” Partner organisation

Some interviewees described the capacity-building effects of empowerment – when we find empowerment we are able to help others to do the same. This is one of the main indications that LCiL makes a lasting, sustainable impact.



Values: Rights

What focus group participants said about the role of rights at LCiL:

- “ Rights are the means to live independently ”
- “ It comes across in every workshop, it's intrinsic in LCiL ”
- “ Rights are often misunderstood or poorly explained. But LCiL help you understand your rights as individuals ”
- “ You know what you should be able to access, instead of having a feeling like you are begging. It makes it a more equal process ”

Examples of LCiL's impact on people's rights are given in **Section 2** above. The quote below and the video shed more light on how the organisation achieves this.

“ Even if LCiL can't do something for you, they can give you the knowledge and point you in the right direction where you should be looking and what you should be asking, and what you are entitled to ask for. It gives you more confidence when dealing with authority, and if you are having to argue your case ” Dugald



Lia's story

The right to be courageous

“I am an immigrant in this country and for years I have been mistreated with my needs around disability. Services were trying to shake me off, trying to convince me that I didn't need support, but nobody ever showed an interest in what was happening to me.



I was desperate at that point and I just needed help. I had heard really good reviews of LCiL. They were great at getting through to me and putting me at ease. They had a lot of questions that nobody had asked me before, so it showed a genuine interest in what was happening to me. I was treated as a person, as an individual.

The very first step was being invited to a training session. It was 'Know Your Rights', which was really an eye-opener. After I had done the training, I left the building as a completely different person.

“LCiL are really good. They equip you with the right skills and give you a voice”

I was still struggling on my own, so I had to start to use the Independent Living Service. That made a huge difference. Once LCiL got involved, everything changed. Within a couple of months I was equipped with a care package and a PA.

LCiL are really good. They pay a lot of emphasis on pumping up your self-esteem. They equip you with the right skills and give you a voice. They make you face reality, but in a way that you feel that you have control. They not only understand the issue, but they also want to do something for you. That is the main difference.

I don't have this fear or guilt to speak about what I need any more. I have a PA. I am a very different person. Most of the time I feel confident, I don't let people just step over me. Just to know that LCiL are there makes me a lot more conscious and a lot more courageous”

Values: Peer support

Focus group participants discussing peer support:

“It’s about two equals meeting, not a professional supporting me because they are being paid”

“People with lived experience sharing knowledge and skills for the benefit of all involved”

“Exchange and development of information and strategies”

During the review’s interviews with LCiL service users, people were never more animated and enthusiastic than when describing the enjoyment, equality and empowerment they find through peer support.

Peer support takes many forms at LCiL. Formally, there are monthly peer support groups, and one-to-one support from specially trained peer mentors. Informally, it comes from the two-way acceptance, information and encouragement that people provide each other. The everyday nature of this was even evident during the review. For example, participants paused a focus group to allow them to support and advise one of their members on a query they had.

Peer support is clearly one of LCiL’s most valuable and powerful assets, but it should be noted that trained volunteers and informal peer support are not free. LCiL provides training, support, time, space and practical resources (e.g. transport and catering for groups) to ensure peer support happens safely and effectively. These all need to be resourced appropriately, which should be kept in mind for funding the organisation’s work.

“Interaction with the people that were in my group was as important as working with the tutor. The tutor was disabled as well, but everybody had their own experiences and picking up on different issues was enlightening” Jeff



“Peer support takes many forms at LCiL”

Ashleigh's story

The value of peer support



“My name is Ashleigh, I first came to LCI two years ago looking for work and volunteering opportunities. And LCI were recruiting peer supporters, people to help others with specific problems. From that I got involved in the peer support group as well. We have worked on some big issues, how to tackle that system, getting unstuck, finding work, that type of thing.

Everybody has different experiences, so everybody brings a different element to the group. And even in peer support groups, people learn about each other and things. You become quite close to people. It's really nice to have a group of friends that you know you can have deep conversations with.

I feel like if I've got an issue, then with peer support you are not dealing with it by yourself, you're able to come in and ask other people what they think. It goes on from that. I have a network of other people, we can check up on how everybody is doing. Going to the peer support group means that you have that dedicated time to help each other.

It is really good to come to the peer support group and have your rights recognised

All the members of the group are in the same situation, it is not a staff-based relationship. The staff very much facilitate it, but they don't really have much to say in the meetings. It teaches us that we can help each other.

The main difference it makes is that you know that people are there for you and you know that you can come with things that bug you. It is good that it emphasises the fact that you can have choice and control. If you are having a problem with your support and things like that, you can come to a group and they will say, remember that it is your support. It is really good to come to the peer support group and have your rights recognised. It is very person-centred.

It is also important to celebrate successes as well. If something has gone really well, we can go and celebrate it. We can share opportunities, bounce ideas off each other.

I wouldn't have as much confidence without peer support. I am a very confident person now. It is important to come even if you don't have an issue because you never know, you could help someone else”

5. LCI's Services

This section provides an overview of LCI's main services, with comments from service users who have used them. Each section also begins with a short description of the service from a service user's perspective, developed during the stakeholder focus group.

► Independent Living Support

“Managing to live my life successfully”

Service user

What does the service provide?

Information and one-to-one support to explore, decide on and manage self-directed support packages.

“Independent living is not about being left to your own devices to get on with things, it's about having the right support in place to allow you to make informed decisions about your life, what you want to do, and how you are going to achieve that. That is what the Independent Living Team is here to help with”
Iain, staff member

The most common example of the Independent Living Team's impact was giving people the information and confidence they need to employ Personal Assistants (PAs). This was described by many as the main enabler of independent living.

“They made it a seamless transition from being in an institution to living independently. When I came out of hospital, it was all in place” Dugald

“Knowing that there is a backup team there at LCI if ever we need it reassured us about employing PAs” Jeff



The review's findings accord with the 2018 service user survey:

- 92% of respondents had increased confidence in employing PAs.
- 100% reported that employing PAs helped them do the things that are important to them.
- 95% of service users have confidence in the team's competence and knowledge and 96% value the service and would recommend it to others.

In the survey, service users were asked an open question about the impact of the Independent Living Service on their lives. Answers were grouped into the following themes (in order of prominence):

- Staying independent and having choice
- Improved care
- Life changing
- Reduced stress, increased confidence and wellbeing
- Being able to stay in own home
- Quality of life
- Getting out more, connection to community

► Financial Management Support (known as Payroll service)

“Manages money and finances for my support”

Service user



What does the service provide?

LCiL's payroll service helps with all aspects of administering and paying personal assistants (PAs).

Support is provided by phone, email, and face-to-face in the LCIl office or in people's homes across the Lothians.

People commonly described the increased confidence, reduced stress and better use of time and energy that come from using the Payroll service. It is seen as expert, with up to date knowledge and practical solutions for all aspects of employing PAs.

“It has made it possible for me to have PAs without having to have the worry and hassle of having to do the administration as well as that” Helen

“Instead of me advertising and using my address, they will put up the adverts for me online and then they field it and pass on any applications. That is an awful lot of management time that I'm spared. They are extremely good at what they do and I know I can trust whatever they say, that they would always look out for my interests. Even just simple things, like advising on what could be on the application form, changes in terms and conditions” Dugald



Again these findings are backed up by the 2018 service user survey, where:

- 95% of service users reported being more confident about managing their direct payments and being a PA employer.
- 97% of services users value the Payroll service's work and would recommend it to others.
- 96% describe the quality of service as 'excellent'.

Analysis of survey comments about the Payroll Service identified the following themes:

- ▶ Employing a PA/managing payments is made possible or easier
- ▶ Reduced stress/increased peace of mind
- ▶ Makes life easier and saves time
- ▶ Essential/couldn't cope without it
- ▶ Improves quality of life and independence

“I would not feel confident to use direct payments to employ a PA without this support. My daughter's quality of life would be much poorer” Survey response

“When setting up Self Directed Payments the process can look very daunting. Having such good support gives you confidence to proceed” Survey response



“95% of service users reported being more confident about managing their direct payments and being a PA employer”

Dugald's story

A seamless support

“My first engagement with LCiL was in 1996. I was captain of my work's rugby team, I went to make a tackle and suffered a spinal cord injury. I was transferred through to the spinal injuries unit. As I went through my rehab, it came to a point where I was going to be released, and that is when LCiL sent through an independent living officer.



I had no idea how life would work post-injury, what the nuts and bolts of living independently were and what to expect. LCiL were very prominent in making sure that others were aware what potential issues were, from their experience of other disabled people living in the community. A number of times, this caused people to rethink the process of discharge. LCiL spent extra time with me, talking me through the whole thing.

LCiL made it a seamless transition from being in an institution to living independently. When I came out, it was all in place – we had PAs recruited, shifts organised. If you are going to become a PA employer, then you're going to have to know your rights and responsibilities, consider things like advertising, job descriptions, timetabling – none of these things had occurred to me. LCiL went through it with me again and again, drawing up the job descriptions, adverts and so on.

It all afforded me the ability to come out of hospital, live in a house on my own, be able to get up and go to bed when I wanted, go to the cinema, go and do anything I wanted, make my appointments, and begin steps on the way to me going back to work.

It just meant that I carried on my life. It wasn't the same life as I was part of prior to my accident, but I was doing much the same things. And I was able to do that from a comfortable, stable environment where I had the support to allow me to do that.

As a disabled employer in Edinburgh, in order to pay my employees I have to do a payroll each month, and I use the LCiL payroll. I've never had any problems with it. I pay a little bit each month for the payroll service, but that is given to me from the council anyway. So, I'm not contributing anything to this organisation that has allowed me for the last 20-odd years to go from one life to a similar one. I felt that I could contribute my time, so I joined the Board. It's very challenging at times, but it is rewarding when I see the organisation continuing ”

► Grapevine

“Independent, confidential information and advice on any disability” Service user

What does the service provide?

Information and advice on any disability matter including benefits, transport, housing, social work services, holidays and much more.



The most common example people gave of using Grapevine was for support with Personal Independence Payment (PIP) applications and assessments. This is unsurprising after several years of welfare reform that most interviewees described as extremely challenging. For the same reasons, external partners also value Grapevine's expertise in this area. However, other examples given included holidays, pensions, crisis funding, aids and adaptations, and other support services.

“I was apprehensive about coming in because I didn't really know where to start with this (benefits) form. (The staff member) was great, she asked questions, I just talked to her and she wrote stuff down. She helped with the whole form” Rohan



These comments are backed up by the 2018 service user survey:

- 100% of survey respondents value and would recommend Grapevine.
- 100% find its information to be clear and well presented
- 97% reporting confidence in staff's competence.

“Very good at what they do. They helped and supported me. The work that they do is fantastic” Survey response



Survey comments about the Grapevine Service can be grouped into four main areas of impact:

- Support with PIP and benefits
- Increased independence at home and family life
- Feeling supported
- Being connected to useful information and other services.

“My home is now adapted for my needs. My husband as principle carer is now able to have more breaks. As my directly employed carers are familiar with my specific needs, it provides stability” Survey response

► Self Directed Support Programme (Peer support)

“Matches people who have accessed systems to those who want to be empowered to do the same” Service user

What does the service provide?

At the heart of the Self Directed Support Programme are peer support activities and the development and contribution of LCIl Champions.

Workshops, peer support groups and one-to-one peer support to help parent carers and disabled people in the Lothians increase their knowledge, skills, confidence and resilience.

LCiL Champions are also available to share their lived experience at conferences, events or training programmes, or to become members of working groups or committees. (For more information on Peer Support and its impact, see **Section 4**, pages 26-27.)



► Training Service

“Provides information, skills and direction, tailor made for us” Service user

What does the service provide?

Provides workshops for individuals or organisations, on topics such as disability equality and self-directed support.

The training programme has been a core part of LCIl's services for many years. In the last two years the range and variety of workshops has had to be reduced to adjust to changes in funding. This is regrettable, as several interviewees described workshops as their gateway to the organisation – and to transformations in their lives. Three people described leaving their first LCIl workshop as 'a changed person'. Several reported fundamental changes in their identity and confidence when their experiences as disabled people were validated. Learning about rights and the social model of disability were particularly transformational.

“The first workshop was really an eye-opener. I already had some suspicions that the system was not working well, that I should have been treated better. After I had done the training, I left the building as a completely different person” Lia

“I attended LCIl courses and learned about the social model of disability. And although that was how I'd always seen it in my mind's eye, suddenly it was properly clear to me and this began to change my attitude towards myself” Martin



Jeff's story

Taking the plunge

“In June 1999, an undiagnosed tumour haemorrhaged in my spine just below my neck and left me paralysed from the shoulders down. I was in hospital for fourteen months, and about nine months of that was because I didn't have a support package to go home to.



High on the agenda was residential care. Someone from LCiL came out to see me at the hospital and explained about direct payments. He then arranged for someone who had a PA to visit me. It was quite an eye-opener. The lived experiences of being a PA employer and what she could do, what the role of the PA was.

We decided then that that was the route to go on. We got together with the representative from LCiL and we talked through what our needs were. He was able to guide us in quite a few aspects.

LCiL were running a course called Taking the Plunge, about living choices. The interaction with the people that were in my group was as important as working with the tutor. The course gave me a good grounding and I felt fairly confident so we started recruiting PAs, to have a team ready and in place when I got discharged from hospital. The biggest worry that I had was the payroll. We got reassured on the course that it was possible. Knowing that there is a backup team there at LCiL if ever we need it reassured us.

**“I don't know where I would have been
if I hadn't been introduced to LCiL”**

Through the people I was involved with in that initial group, I met other people who are friends now. I got involved with other disability organisations. I'm now chair of the Scotland Against the Care Tax campaign and I am also getting involved in the political aspects of things.

I don't know where I would have been if I hadn't been introduced to LCiL - possibly in residential care. I don't know if my marriage would have survived. I think I would be isolated. I wouldn't have had the contact with other disabled people that I have now, or the understanding of what life could be – the positive aspects of being disabled”

6. Future wishes

Although the review found overwhelmingly positive evidence in support of LCI's values, services and impact, it also invited people to list 'three wishes' for improving the organisation in future. These are listed and illustrated below, in order of the number of people who identified each wish. (Quotes in this section have been anonymised.)

It should also be noted that the same wishes were raised at a recent service users' engagement event. The organisation is therefore aware of these and has already included them in the information that is being used to develop the LCI 2018-22 Strategic Framework.

► Funding

10 people wished for more funding for the organisation. Three of these identified survival and continuity of service as immediate priorities. Two others highlighted unmet need for advice services. Others suggestions were for developments including employability support and more workshops.

“I would like there to be more classes, but you would need funding for that” Service user

“One of my wishes is that LCI is able to just keep doing what it's doing” Service user

► Promotion and profile

Seven people wished for the organisation to have a higher profile and promote itself better. Staff were more likely than service users to be aware of this, but external stakeholders also saw it as a priority. Charities often find promotion challenging, due to limited resources or diffidence about highlighting 'need' – or celebrating success. Something which might make this easier for LCI is to see it as a way to make peoples' voices heard.

“I think they should be a lot better known than they are, for what they do. I don't think they get enough credit for the difference they make to people's lives” Service user

“I wish that they did sell themselves better. I think they short change themselves. More PR, or more in your face opportunities for people” External partner

► Campaigning and influencing

Staff, trustees, service users and external partners all suggested that LCiL could be more active in using its knowledge and expertise to influence policy.

“ LCiL has so much understanding of how important it is to disabled people to have choice and control over their own lives, so I would like to see LCiL campaigning and working with local and central government to make these rights possible for more disabled people ” Service user

“ They have a voice that may be able to change policies. Especially with some of the benefits becoming devolved. It would seem an optimum time to have a bit of an influence at a political level ” External partner

► More members

Four service users wanted LCiL to have more members and service users, and more active involvement, so that more people can benefit from its support.

“ I wonder if there is a way that LCiL can communicate more effectively with the service users to enable them to understand the value of getting involved in various different things, and how it will help them ” Service user

“ I would like to have a bigger, more active membership ” Trustee

► More support for benefits claims, from application to appeal

LCiL does not have the capacity to meet demand for its specialist benefits advice services. Staff, service users and external stakeholders would all like it to provide end-to-end support, from application to appeal.

“ It can make a massive difference, actually being there at the assessments. If that was something that Grapevine could offer in the future, if they had the staffing capability, that would be amazing ” External partner

“ I would like to see LCiL be able to follow through, right through to appeal ” Service user

► Bigger team

External stakeholders hold LCiL in high regard and are particularly keen for it to have more staff. This would enable more home visits for clients, reduced waiting lists, more flexibility, and more links with partner organisations.

► Social and out-of-hours activity

Three service users suggested LCiL could facilitate more social activities or links for people, for example evening and weekend social events and online forums to reduce isolation. Online courses were also suggested.

► Social work links

Three members of staff felt that greater links with social work teams would raise awareness, encourage referrals, and ensure seamless support.

► Other

Two service users suggested LCiL could provide advocacy support. Two others wished for dedicated emotional support alongside other services. Other individual wishes were for housing support; a carers' support group for spouses and partners; and working with young disabled people to raise their awareness of PA employment. One final wish was to have LCiL everywhere!

“ I think there should be LCiL in every town, city in the country, or a service like it. It is a system that works ” Service user

LCiL's roots are in the Independent Living Movement

The Movement took off because disabled people were frustrated at the lack of control they had over their lives. Through the Movement and Disabled People Organisations, disabled people come together to claim their rights and offer practical solutions for change. These crucial contributions to societal change are supported by a varied and solid body of analytical work undertaken by disabled activists and universities.

“ How a disabled person sees her or himself may not only affect the way problems that they face are identified but also influence the way help offered by others is accepted or rejected. Seeing oneself as suffering because of an impaired body or function could lead to demand for assistance to become as 'normal' as possible. On the other hand, if discrimination is seen as causing the difficulties then help aimed at providing equal opportunities could be the preferred option. How disabled people identify themselves, then, can be very important in developing intervention strategies for services as well as helping them to help themselves. The question is what is this identity? ”

Vic Finkelstein, disabled activist and founder of the Independent Living Movement (1993 'Disabling Barriers – Enabling Environments')



LCiL would like to thank the generous support of the Garfield Weston Foundation for funding this report.

Lothian Centre for Inclusive Living (LCiL)

Norton Park Centre, 57 Albion Road, Edinburgh EH7 5QY

Telephone: **0131 475 2350**

Minicom: **0131 475 2463** Fax: **0131 475 2392**

Opening Hours: Monday to Friday, 10.00am to 4.00 pm

www.lothiancil.org.uk

