



Are YOU ready to play...

'Whose Choice Is It Anyway?'

Lothian Centre for Inclusive Living (LCiL)
Rights and Choices for Disabled People

Independent Living Service
Grapevine Information Service
Training Service
Payroll Service
Your Call Counselling Service

Whose Choice Is It Anyway?

A game of chance, luck, jeopardy and fortune!

★ The Rules of the Game...

Be in it to win it!

- ★ Remember to fight for your rights
- ★ Be determined, don't take no for an answer
- ★ Join lots of waiting lists for services
- ★ Be assessed again and again
- ★ Fill in loads of long forms
- ★ Be prepared to give out all your personal information to lots of professionals
- ★ Write heaps of letters
- ★ Go for oodles of medical interviews
- ★ Know your rights and claim what is yours by right
- ★ Aim for the JACKPOT – a full and independent life!



Remember that if you give a wrong answer you could lose everything!

If you don't know the answer, you can always

Ask the Audience!

(Please keep in mind that the audience cannot be relied upon to give the right answer because much of our society still views disabled people's lives as tragic and burdensome.)

Or you can Phone a Friend!

(Remember you may be charged premium rates for calls to friends and the text phone will probably not be working.)

Awards of benefits and other money are not guaranteed and may go up and down according to the amount of money available in the jackpot at any one time. This should not be confused with **disabled people's rights** which, although they do not change, they do seem to be influenced by the money available in the budget.

State of Play

In 2009 the Scottish Government, the Convention of Scottish Local Authorities (COSLA) and Independent Living in Scotland (ILIS) all signed up to a new shared vision of Independent Living for disabled people in Scotland. Disabled people across Scotland would have equality of opportunity and enjoy the same freedom, choice, dignity and control that other citizens take for granted – at home, at work, in education and in the social and civic life of the community.

Here at the **Lothian Centre for Inclusive Living (LCiL)** we are inspired and encouraged to be a part of this new vision. However, we are also frustrated to witness that in reality many disabled people still face discrimination and continuous barriers to Independent Living.

Disabled people still live in poverty and, with increasing financial pressure on public services, many are extremely concerned that the right to live independent lives is a luxury which can only be afforded by non-disabled people.

Within **Community Care** you may be lucky enough to live your life as you choose or you may be reduced to merely surviving with minimum support. This can depend on where you live, how long you have been receiving your care package and how it has been reviewed, as well as whether you have been assessed as having critical needs. The current trend is to provide minimum support and many disabled people feel that the quality of support is determined more by chance than a right to life with dignity.

So, why not have a go?

To find out about the game, check out the following Rounds:

- | | |
|---|--|
| ★ Round 1:
Community Chance | ★ Round 7:
Strike it Lucky |
| ★ Round 2:
A Question of Choice | ★ Round 8:
Making Connections |
| ★ Round 3:
Independence Fortunes | ★ Round 9:
Play Your Assessments Right |
| ★ Round 4:
Beat The cuts | ★ Round 10:
Opportunity Knocks |
| ★ Round 5:
The Price is right | ★ Round 11:
Beat the Banker |
| ★ Round 6:
I'm Sorry I Haven't a Clue | ★ Round 12:
This is your Life |

COMMUNITY CHANCE ...and this is a biggie!

Will you take part in the Postcode Lottery?

Round 1

★ **What do you think Community Care should be about?**

- a) Support with day to day tasks – to work, enjoy a social life, take part in leisure activities and live an ordinary life. **(The right answer!)**
- b) A social club.
- c) Meeting basic needs only – help with 'toileting, bathing, dressing and feeding'.

★ **Are you on the money?**

Disabled people want support rather than care to get on with their lives. **Community Care** should be about disabled people having the right to be equal citizens in an inclusive society. In Scotland, however, over 70% of local authorities provide services only to those whose needs are considered critical or substantial. Community Care budgets will be the target of forthcoming cuts, further reducing the chance of a good quality of life for increasing numbers of disabled people. Is this really what Community Care should be about?

★ **Is support an accessory for disabled people which can be disposed of when the finances in society have been badly managed and savings have to be made?**

Support for disabled people to live independently is a basic human right which makes the difference between being a part of society or being excluded from it.



LET'S PLAY 'A QUESTION OF CHOICE'!

In this round you could win the right to have the same choices and opportunities as everyone else. Are you going to Run the Risk?



Round 2

★ **Why do disabled people need support to manage their Self Directed Support package?**

- a) It's too much of a risk for disabled people. They will only end up making mistakes.
- b) It's too complicated for most disabled people. Put them in institutions where they don't have choices.
- c) Disabled people with the appropriate support can better understand the rights, responsibilities and choices involved in opting for Self Directed Support.

(The right answer!)

★ **Play or Pass?**

LCiL believes that any disabled person should have the choice to benefit from Self Directed Support and to live a more independent life. This means ensuring people have the right support, right at the start. It is our priority to ensure that users of LCiL services have support to achieve the best outcomes for themselves.

'I could not live independently without Personal Assistants and the advice I get from LCiL. They allow me to live in my own home and to do the things I want to do when I want to do them.'

Over one hundred service users took the time to respond to our recent survey.

★ **Our survey said...**

90% of service users stated that as a consequence of support from LCiL they were more confident about independent living. 96% of service users were satisfied with the level of service and the support they received.



LET'S PLAY 'INDEPENDENCE FORTUNES'!

You could win the right to be in control of your own life! If You Lose, You Leave with Nothing.

Round 3

★ Do User-led Disabled People's Organisations make a difference?

- a) Yes. Disabled people themselves say that Disabled People's Organisations make a great difference. **(The right answer!)**
- b) No. Some parents, carers and professionals know what's best for disabled people.
- c) No. They are always banging on about rights.



★ Are you ahead of the game?

User involvement gives disabled people a collective voice and ensures that services are accessible and do make a difference.

The governance, service management and delivery of **User-led Disabled People's Organisations** all involve disabled people. LCiL have a staff team with the necessary knowledge and skills including direct experience of disability to make them experts in their field. Therefore, they have a vested interest in making sure that services and support are correctly provided to those that need them.

Since its beginning, LCiL has used a **holistic approach** to support individuals and worked to develop effective partnerships with other organisations.

★ **Promoting independence** is at the core of LCiL's existence and as such supports the Government's strategy to ensure that disabled people have a bigger say in their own lives and what happens to them.



LET'S PLAY 'BEAT THE CUTS'!

Charity – the Final Frontier?



Round 4

★ What changes will Disabled People's Organisations have to make to survive the funding cuts?

- a) We'll use carrier pigeons instead of stamps for the mail.
- b) We'll be forced to cut our services **(The right answer!)**
- c) We'll write to Jim'll Fix It.

★ Let's take a look at the Scores on the Doors...

LCiL, like many user-led Self Directed Support organisations, is facing an uncertain future with regards to funding.

★ **Strike 1...** against user-led support organisations as Direct Payments Caledonia is forced to close. Services are split up and put out to tender by Moray and Aberdeenshire Councils. A financial insurance company is offered the contract for employment law support and an unrelated service provider wins the contract for Self Directed Support.

★ **Strike 2...** Forth Valley Direct Payments Support Service (FVD PSS) is taken in house by Stirling Council. The Council withdraws funding for the service provided by FVD PSS. FVD PSS still provides a service in Clackmannanshire and Falkirk.

★ **Strike 3...** Perth and Kinross Direct Payments Support Service is taken in-house. Perth and Kinross Council withdraw funding for an independent service.

★ **Strike 4...** South Lanarkshire Disability Forum is forced to close. Although the management of the Self Directed Support service itself is taken over by SPAEN, South Lanarkshire Council withdraws funding from the Disability Forum.



It's not quite Total Wipeout.... yet!

LET'S
PLAY 'THE
PRICE
IS RIGHT'!

So... Come On Down!



Round 5

★ How will you ensure that you have a decent income to live on?

- a) Bake cakes and sell them to all my friends.
- b) Campaign for a decent income for disabled people to live on. **(The right answer!)**
- c) Go for a medical interview and have my Disability Living Allowance cut.

★ Entering The Benefits Maze...

Disabled People are twice as likely as non-disabled people to live in poverty. Over half of all disabled people are not in employment and around half say that they have no savings at all. Disabled people also face extra disability related costs including having to pay for things like equipment, taxi fares, adapted vehicles, housing adaptations and contributions to their support package. Poor decision making in the benefits system often drives people into spiralling debt and further poverty.

Grapevine, LCI's information service, provides advice on disability benefits and other financial support, thereby supporting disabled people in accessing the money that they are entitled to.



LET'S PLAY 'I'M SORRY
I HAVEN'T A CLUE'!

In this round you could win **BIG PRIZES** including a free trip to the doctor or the **GRAND PRIZE** of a medical assessment with the Department of Work and Pensions!

Round 6

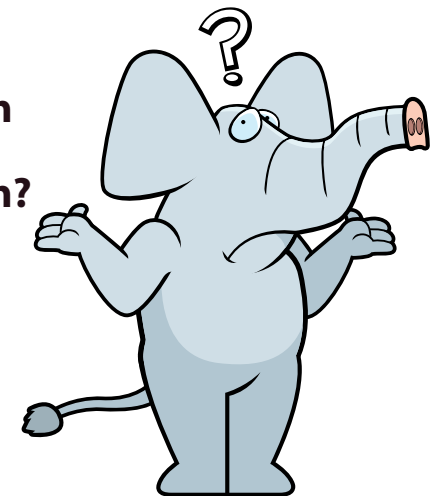
Where can you go for information and advice about your rights and entitlements as a disabled person?

- a) The neighbour's dog.
- b) The back of a cereal packet.
- c) Grapevine, LCI's information service.

(The right answer!)

★ Everyone's a winner!

Grapevine provides free confidential information and advice to disabled people and their supporters in Edinburgh, East Lothian and Midlothian. Grapevine provides advice on disability benefits, access to transport, housing, equipment, community care services, holidays, leisure activities, improving access and tackling disability discrimination. If you are looking for information on any disability issue then contact Grapevine. Don't lose out, claim what's yours!



'When I became disabled, I didn't know what I could get. There are so many things to sort out; my job, my house, getting a wheel-in shower, negotiating with the council, dealing with the whole benefits nightmare! They (Grapevine) helped me apply for DLA (Disability Living Allowance) and it made a big difference.'

In the past year the Grapevine Information Service responded to 2,160 enquiries for advice from 1,340 individuals and organisations in Edinburgh, East Lothian and Midlothian. The majority of our enquiries came from individual disabled people.

LET'S PLAY 'STRIKE IT LUCKY'!

Are you going to Win, Lose or Draw?

Round 7

★ What can you do to access support to live independently?

- a) Apply for Direct Payments and take control of your own support package. **(The right answer!)**
- b) Get a free trip to Lourdes and at least you'll get some sun!
- c) Go through 3 social work assessments, 2 occupational therapy assessments and 1 housing assessment, then plead, beg and scream for help!

★ Countdown to independence...

With the right package, **Self Directed Support** allows disabled people and people with long-term conditions to be in control of their own support and to have choices about the support they need.

LCiL will help you explore the possibility of Self Directed Support, helping you to understand what is involved and, if you choose to employ your own personal assistants, LCiL can help you to find, interview and recruit them.



'It has completely changed my life. I now have a life again. Before going on to independent living I thought life had finished. I get out a lot more and all my daily requirements are met. What a remarkable change to my life and mental state.'



LET'S PLAY 'MAKING CONNECTIONS'!

In this round you have the chance to get to know your fellow contestants better. Listen Carefully as You May be Tested Later on your knowledge.

Round 8

★ How can Peer Support help disabled people?

- a) We can all sink in the same boat.
- b) We can share how tragic our lives are and give each other lots of pity.
- c) We can share experiences, deal with challenges, learn together, find solutions, have some tea and biscuits, you can have a whinge if you want! **(The right answer!)**

★ Going for GOLD!

LCiL organises **Peer Support Groups (PSG)** for Personal Assistant (PA) employers. Peer Support is recognised as one of the 7 needs of Independent Living as identified by the Disabled People's Movement which is underpinned by the Social Model of Disability.

In Edinburgh, the PSG is facilitated by one of LCiL's **Independent Living Officers** who has personal experience as a PA employer. The meetings have a relaxed atmosphere that allows both the more experienced employers and those new to it to talk about the issues that are affecting them. The topics vary but include things like staffing issues, contingency money, advertising for staff and changes to employment law. The PSG have identified some areas that they would like to campaign on and, by being united, don't have to battle alone!



LET'S PLAY 'YOUR ASSESSMENTS RIGHT'!

You could go on to enter the Independence Lucky Dip and Double Your Choices!

Round 9

★ Where can you get impartial advice on, and support with, your Self Directed Support?

- a) Any hairdresser.
- b) Radio 4's Gardener's Question Time.
- c) LCIl's Independent Living Service. **(The right answer!)**

★ The answer is right here!

LCiL's Independent Living Service can provide the following support to disabled people: one to one advice on self directed support, home visits to support service users, help with recruiting and managing Personal Assistants (PAs) and advice on assessments depending on the Local Authority area.

'LCiL has enabled me to stay in my own home. I cannot get the necessary services in any other way. My health couldn't be catered for in residential care. LCIl services suit your needs. LCIl's counselling service has also helped – emotional support – help in every aspect.'

★ Our survey said...

88% of service users stated that as a consequence of support from the Independent Living Service they were more confident about independent living. 84% of service users stated that the Independent Living Team had enabled them to live more independently. 79% of service users stated that support from an Independent Living Officer helped them decide to go ahead with Direct Payments.



LET'S PLAY 'OPPORTUNITY KNOCKS'!

This is the one where you... Pick a Category!

Round 10

★ What would help you to become a good PA employer?

- a) Watching *The Apprentice* and practising saying 'You're Fired'!
- b) It isn't rocket science, honest! LCIl's Training Service can help. **(The right answer!)**
- c) Getting a PhD in employment law.

'(What I got from training) to be more in charge of support staff, set own job description, hire people so that I can rely less on family.'

★ And your categories include...

LCiL Training focuses on issues surrounding Independent Living and in particular being a Personal Assistant (PA) employer as these topics have been identified as most relevant to the disabled people we work with.

LCiL's Training Service aims to create learning opportunities where disabled people can feel comfortable and supported, encourage disabled people to develop their self awareness and self confidence and support disabled people who want to gain information and practical skills with regard to becoming a PA employer.

Training takes place in a relaxed, friendly and supportive learning environment and includes a mixture of information giving/sharing, discussion and practical group activities. All our courses are delivered by experienced disabled trainers.

★ Our survey said...

75% of people who came on courses felt that the training had made a positive difference to their life. 75% of participants felt the trainers worked in an inclusive manner and 70% felt that they had not been able to take up training offered by organisations other than LCIl due to inflexible arrangements.



LET'S PLAY 'BEAT THE BANKER'!

What's the Formula? Will you use an abacus or a calculator?



Round 11

★ **As a new Personal Assistant (PA) employer – how would you make sure your employees' wages are calculated correctly?**

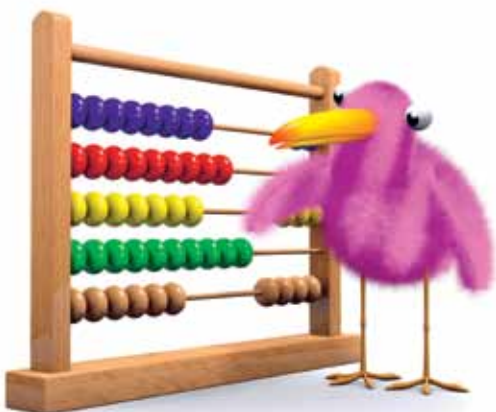
- a) Ask Ozzy Osbourne.
- b) Use LCI's Payroll Service.
(The right answer!)
- c) Guess! (If I get stuck, I will pay my PA with buttons.)

★ **The winning combination!**

LCI's Payroll Service reduces the anxiety of being an employer. The service calculates employees' wages, any National Insurance (NI) and PAYE tax due, and sends monthly payslips and payroll reports to each PA employer. The service also liaises with HMRC as needed and submits end of year returns on behalf of service users. The Payroll Service is tailored to suit the individual needs of each PA employer.

★ **Our survey said...**

99% of payroll service users said that LCI's payroll team was very helpful or helpful; 90% indicated that they feel more confident. Out of those surveyed 97% were satisfied with the payroll service and 82% said that they are now able to live more independently.



'Had I not had their support at times when I needed it I would be really struggling. I know where to go when I need help. Payroll was something that I had not had to do before. Without their help I wouldn't be confident at all; need to live your life and do other things.'

LET'S PLAY 'THIS IS YOUR LIFE'!

In this round you really are 'In Control' of the **HOT SEAT**.

Round 12

★ **What is Your Call?**

- a) LCI's free national telephone counselling service run by disabled people for disabled people. **(The right answer!)**
- b) The name of a television game show.
- c) Your round at the bar.

★ **Making a difference...**

Your Call is staffed by professionally qualified disabled volunteer counsellors and operates three days a week between the hours of 11am and 3pm, and in response to demand one evening a week. Your Call is unique in Scotland.

★ **Our survey said...**

95% of the people said that they were satisfied with the service. 87% said that Your Call was different from other counselling services. 92% agreed that the service is easy to use. 96% (of which 61% strongly agreed) agreed that counselling at Your Call improved their wellbeing.).

'Being a telephone service means that you can have the opportunity to access a counselling service even if you aren't well enough to get out. It also means you don't make your symptoms worse by going out, so saving health energy and not increasing the pain.'



A WAY OUT OF THE MAZE!

We can't give you a Golden Globe but we can make life easier for you through appropriate support, timely help and extensive experience.

Who are we talking about?

Why, user led Disabled People's Organisations of course!

User-led organisations are those where the people who the organisation represents or provides a service to, have a majority on the Management Committee or Board, and where there is clear accountability to members and/or service users. In this case, the organisations represent disabled people.

'We promote community ownership and true empowerment because we focus on our service users and positive outcomes for stakeholders. We will not compromise on quality.'



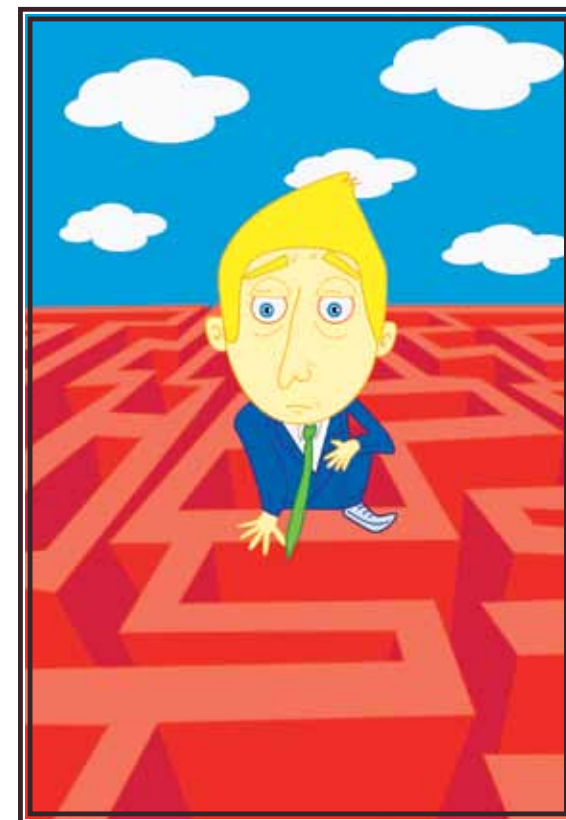
User-led organisations adhere to the following standards...

- Work from the Social Model of Disability
- Promote Independent Living
- Promote people's Human Rights and other legal rights
- Is shaped and driven by the initiative and demand of the organisation's service users
- Is Peer Support based
- Covers all local disabled people, carers, and other people who use support either directly or by establishing links with other local organisations or networks
- Is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age
- Recognises that carers have their own needs and requirements as carers
- Engages the organisation's constituents in decision making processes at every level of their organisation.

...which makes sure they work for you!

We promote community ownership and true empowerment because we focus on our service users and positive outcomes for stakeholders. We will not compromise on quality.

Both the UK and the Scottish Government recommend that there is at least one User-led Disabled People's Organisation in each local authority.



DIDN'T YOU DO WELL!



Good game! The results are now in and let's see if anybody has won the Cuddly Toy...

'It makes sure I'm still alive! If I didn't have a PA I couldn't live alone. Don't think I'd like an institution – no quality of life... I have a life, have a cat, see family and friends. Yeah there are big physical limitations but I think they are do-able. Otherwise, couldn't happen. My life is how I want to live it. I make my own decisions. I make my own mistakes...'

'It means I can have some self respect and self worth. I don't need to disturb friends and family - they don't need to be my carers. I can be "Myself" in the outside world and live my life the way I want to. It helps my employment situation and progress in my career.'

'We have it for our daughter, it has enabled her to play better with her sister, developed her play skills, supported us on outings, helping with social excursions and visits to doctors/hospitals. Given us respite so one parent can have a few hours off.'

'It has allowed me to gain the individual bespoke support that I wanted and needed. It has given me the confidence to deal with my own affairs.'

'It allows for much more social activities, enabling me to mix with and meet new people as well as learning to travel further afield independently.'

'It was empowering to have good clear information, it reduced my anxiety and helped with decision making.'

'Counselling has made me stronger. It has given a big boost to my confidence to say I can do and I can cope. It has helped me overcome my fears. It has given me options.'

'It allows for much more social activities, enabling me to mix with and meet new people as well as learning to travel further afield independently.'

'I am able to have time away from my parents and be with people my own age. It allows me time to go to the cinema, bowling and swimming, and encourages me to socialise with new and old friends.'



And finally...

A very BIG thank you to all of you, our service users, members, stakeholders and of course – our audience!

They think it's all over... and it soon will be if we all don't keep playing the game and defending the rights of disabled people.

So where on earth do you go from here? Why back to the very beginning of course!

See you next time on...

Whoose Choice Is It Anywaaay!!!



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★ Grapevine Disability Information Service

A free, confidential information and advice service for disabled people and their supporters in Edinburgh, East Lothian and Midlothian.

Phone 0131 475 2370

Email grapevine@lothiancil.org.uk



★ Your Call Telephone Counselling Service

A Scotland wide free telephone counselling service by disabled people for disabled people.

Freephone 0808 801 03 62



Information is available on request in LARGE PRINT, Audio, Braille, community languages and in an Easy Read format.

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