



DIRECT PAYMENTS
for
INDEPENDENT LIVING

Company Limited by guarantee with no shareholders.

Registered Number 4854897, in England

And Registered as a Charity, Number 1107079.

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CiILK

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BRIEF HISTORY AND POSITION TO DATE

CiLK was formed in April 2002 to support the positive promotion and uptake of Direct Payments and Independent Living¹ for Disabled People² living in Kent.

This followed the KCC Social Services conference 'Disabled People – Shaping the Future' held on 11th March 2002. The conference focused on how KCC Social Services Directorate, as the key player in Kent, could contribute to the promotion of choice and independence for disabled people, empowered by the way Social Services carries out its functions.

The conference included a presentation on the KCC 10 year strategy 'Active Care'; information on the new KCC Direct Payment scheme and the promotion of independent living. There were guest speakers from Disability Awareness in Action and Southampton Centre for Independent Living.

Up until this time disabled people in Kent had been struggling to set up a Centre for Independent Living³ but had not been supported or able to gain funding to achieve it.

Initial core funding came from KCC Adult Social Services, plus funding for an advocacy project from SCOPE and funding from European Year of Disabled People. We were successful in securing a grant of £174,202 from the Big Lottery in 2006 to fund the first mobile centre for independent living in the country to deliver enabling support services, direct to disabled people in Kent and Medway. Additional funding for a clerical support officer was provided by Lloyds TSB Foundation, RBLI, Smiths charity and from KARC.

¹ See Appendix 1

² See Appendix 2

³ See Appendix 3

ABOUT CiLK

CiLK is a pan-disability organisation run, controlled and managed by disabled people who are all experts by experience. We support disabled people to live independently and campaign for an inclusive society which does not discriminate against disabled people.

We believe that disabled people should have the same opportunities and quality of life that non-disabled people take for granted.

We want disabled people to be able to make their own choices, have control over their lives and be able to live independently in their chosen community. It does not mean doing everything yourself, but it does mean having the support and personal assistance to do so.

CiLK is a Company Limited by Guarantee and a Registered Charity. The current directors are all disabled people providing support services through two staff members and a small team of volunteers, all of whom have a disability and are therefore experts by experience; five also employ personal assistants.

We work to the Social Model of Disability, which identifies the various barriers that people with impairments face as the real cause of difficulty, not the impairment itself. The barriers may be caused by the physical environment, by inflexible or inappropriate services, or by negative attitudes and discrimination. The cause of the disability is usually physical, but its effects are primarily social, whatever the disability is, based on others' reaction to it.

CiLK provide support to people with impairments across the county of Kent, although Medway's system of Direct Payments works slightly differently. Our target audience is primarily those who have expressed an interest in living independently. This is done by managing, monitoring and paying directly for their own 'care' requirements using Direct Payments, the Independent Living Fund or other monies. We are also developing a brokerage project in order to support people receiving personal budgets. (Since 1 April 2009 every new person who contacts KASS and has an ongoing social care need and meets KASS social care and financial eligibility criteria will receive a Personal Budget).

CiLK positively supports Kent Adult Social Services (KASS) personalisation agenda of Self-Directed Support (SDS) that will give disabled people more freedom, choice and control over the type of care and support they require to live independently. The Self Directed Support agenda is a key part of KASS's Active Lives for Adults (ALfA) programme. This is KASS's programme of total transformation of social care in Kent which will deliver both on KASS's 10 year vision (Active Lives) and central government's Transforming Social Care agenda.

Since CiLK's formation in 2002 we have assisted KASS with a conference for disabled people 'Shifting the Balance' and provided training on the Social Model of disability. We continue to work with Kent Highway Services on training and access issues, have contributed to KASS Active Lives 2007-2016 document and helped develop KASS Disability Related Expenditure Assessment (DREA) guidelines.

VISION, VALUES, OBJECTS AND MISSION

OUR VISION

To establish a fully operational centre for independent living in Kent.

OUR CORE VALUES – CiLK is committed to:

- The social model of disability.
- The 12 basic needs required for independent living⁴ as identified by disabled people themselves.
- Creating an environment that is based on social justice, inclusiveness, equality, diversity and dignity.
- Setting and maintaining high professional standards in all our activities.
- Continually working to improve the lives of disabled people in the county of Kent.

OUR OBJECTS

“The ‘Objects of the Charity’ are to provide and promote enabling independent living services direct to disabled people resident primarily, but not exclusively, in the County of Kent by the provision of Advocacy, Peer Support, Advice, Information and other Support and Assistance Services which facilitate their independence as full and equal citizens in all aspects of life and the wider community”.

OUR MISSION

“To enable disabled people in Kent to empower themselves”.

4 See Appendix 4

CURRENT SERVICE PROVISION

We provide accurate up-to-date information on independent living and other related issues, direct to disabled and older people and their enablers / carers. This is paramount if they are to make informed choices about maintaining or regaining their independence. By providing the right information, advice and guidance, we empower and enable the individual to obtain the right solutions to their problem(s) which increases self-confidence and gives them choice and control over their situation. This can also lead to increased opportunities in employment, training, volunteering and education.

Our main strands of work are delivered from our mobile unit, office and outreach clinics, they are to provide:

1. Accurate up-to-date information on access, benefits, aids and equipment, mobility and transport, social care, permitted work, disabled facilities grants, support groups, further education, routes to employment etc.
2. Information on all aspects of independent living and Direct Payments.
3. Advice and guidance on the disability related expenditure assessment.
4. Advocacy for people who may require help to identify their support needs.
5. Access audits, advice, information on inclusivity and disability equality training.
6. Peer Support to encourage the development of local networks of Direct Payments users, via our PA User Group, to share their experience and expertise and provide mutual support.

CiLK is aware of other support services required for independent living that are not provided by us eg counselling services, payroll companies operating in the county and nationally and where appropriate; we will 'signpost' as and when required.

Our experienced PA employers can provide advice, information and practical support on many aspects of direct payments including completing your own payroll and how to employ and recruit personal assistants (PA's).

As a user led organisation (ULO) we believe that many services traditionally provided for Disabled People have resulted in segregation, creating systems which actually increase exclusion and dependence.

We work to create real opportunities for disabled people to live independently and participate in the community.

Our current service provision is directed at empowering or enabling disabled people to lead full and independent lives by assisting them to obtain the care and support to do so. We provide information, encouragement, advice, assistance and support in order to achieve this.

We believe that first-hand experience has great value when giving support and advice to others. We also believe that the most important factor is for individuals to empower themselves by being their own advocate. Peer support, information and awareness of what's available are important elements towards this.

ULO members have first hand experience of living with a disability and provide enabling services to support disabled people choosing to take more control over their arrangements for personal care and support. We believe that independent living is important and aim to raise awareness about Direct Payments and other ways of support as a way for disabled people to have more control over their own lifestyles and participate more fully in the community in which they live.

DIRECT PAYMENTS

What are direct payments?

Direct payments are cash payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council.

A person must be able to give their consent to receiving direct payments and be able to manage them even if they need help to do this on a day-to-day basis.

Who can receive direct payments?

Most people who are in receipt of social services are eligible for direct payments. Disabled people aged 16 and over including:

- Older people
- People with physical and sensory disabilities
- People with learning difficulties
- People with mental health issues
- People with parental responsibility for a disabled child
- Carers who have been assessed as needing services

How do I get a direct payment?

To be considered for a direct payment you have to have an assessment in the same way as you would for any social care service.

If you already have services from Social Services contact your social worker to talk about direct payments. If you have not had contact with Kent Social services before you will need to contact them and request an assessment. They will establish whether you are eligible for help from the department.

What can you use your direct payment for?

The money is for you to use to arrange the services (including equipment) which you have been assessed as needing. Following your assessment your worker will explain the options as to how you can receive your services.

If you prefer to receive local council services they will arrange these for you. If you choose to have a direct payment they will explain how you can get help to arrange this.

Will I have to pay any of my own money towards my care?

You may be required to make a contribution to the cost of your care/support package – just as you may already be paying towards services provided by your local authority. Any contribution you do make is based on your ability to pay. A financial assessment will be carried out by an officer from the local authority before you make any decisions regarding the receipt of a DP.

NOTE: If you incur extra costs related directly to your impairment you can request an individual disability related expenditure assessment (DREA).

If I decide I want a Direct Payment, can I change my mind later?

Yes. You can opt in or out of receiving a DP at any time. Many people experience some problems at the outset as everything is new. But we can discuss ways of enabling you to manage your DP more easily.

Will a DP affect any benefits I receive?

No. Any money you receive from your local authority (LA) as a DP for care, will not affect any benefits you receive from the Department of Work and Pensions. A DP is not liable for income tax.

What are the advantages of direct payments?

- Direct payments allow people to have greater choice and control over their care arrangements.
- They can employ their own staff or contract directly with an agency.
- People in Kent already receiving direct payments are very positive about their experience.

What do you need to consider?

- You cannot normally use a direct payment to pay your partner, spouse or a close relative that you live with.
- Direct payments cannot be used to pay for permanent residential or nursing care.
- You can receive a mixture of social services provision and direct payments eg a direct payment could be used to pay a helper to provide personal care each morning and then you could attend a day centre belonging to Social Services.

Direct payments come from public funds and people receiving them have to keep detailed records and open a separate bank account just for the direct payment. If you do not want to open a separate bank account, KASS can supply the Kent Card which is loaded with your direct payment and provides a new, convenient and secure way of receiving and spending these funds and any top-ups.

NOTE: The Kent Card is a Chip and PIN VISA card.

What if I need help with Direct Payments?

CiLK can provide support to people receiving direct payments. We have five experienced personal assistant employers to help with all aspects of direct payments. They can give:

- Advice on the how direct payments can increase independence.
- Help with recruiting selecting and employing staff
- Guidance on record keeping and managing your direct payments
- Information on insurance and health and safety issues.

If you want total autonomy, choice and control over your life we would recommend Direct Payments.

THE INDEPENDENT LIVING FUNDS (ILF)

The Independent Living Funds (2006), - there are two different organisations usually referred to simply as the ILF – are government funded organisations that, in certain cases, provide additional funding to 'top up' the DP you receive from your local authority.

In order to get funding from the ILF you will need to meet the criteria shown below. It is likely you will be required to pay a contribution towards your care. The usual minimum contribution is half the amount of your Disability Living Allowance DLA (Care) at the high rate.

The eligibility criteria for accessing funding is both complex and strict. At the time you are offered the option of a DP your care manager will advise you whether you are eligible to apply. (The ILF and DPs can also be combined).

The main criteria for ILF funding are:

- you must be in receipt of DLA (Care) at the high rate.
- you must be over 16 and under 65 years of age.
- your local authority must be providing a package of care which costs a minimum of £320 per week.

If you are eligible and have been advised to apply to the ILF, your care manager will assist you to complete the initial application. You will then be sent further forms by the ILF. It's important that you complete and return these promptly.

NOTE: The time taken to access funds from application to receipt of funding can often take 12 weeks or more.

Any money you receive from the ILF must go into the same bank account used to receive your DP. This keeps all of your 'care' funding separate from personal money.

The ILF will require evidence you are spending the money on meeting agreed needs, and will review your payments every two years.

PERSONAL BUDGETS

In April 2009 Kent Adult Social Services (KASS) began their transformation of social care in Kent with the introduction of personal budgets. These changes will give people more freedom, choice and control over the type of care and support they need with a Personal Budget. This is called Self-Directed Support.

- A Personal Budget is given to people who, following a community care assessment of their needs and financial position, are eligible for both community care support and assistance from KASS to pay for it. Certain support that they provide, including residential care, is not included in a Personal Budget. Before KASS can give you any money from an allocated Personal Budget you will need to complete a Support Plan and decide how you want to manage your Personal Budget.
- A Support Plan sets out what you need to achieve to lead as independent and fulfilling a life as you want. It will also outline the cost of any care and support that you need. You can develop your Support Plan yourself, with the help of someone else, or use an organisation like CiLK, or KASS can help you. The Support Plan shows how you intend to spend your Personal Budget to make sure you have the support you need. When the Support Plan is finished it will need to be agreed by KASS before they release any money to you.
- After you have had an assessment that shows you are eligible for support from KASS they will estimate your Personal Budget. This estimate is the amount of money they think you will need to meet your care and support needs and is based on what it would cost them to provide support to you. It gives you an idea of how much money you may have to spend on your support. When you have completed your Support Plan you will be issued with an Actual Personal Budget – this is the actual amount of money you will receive based on your agreed Support Plan and it may be more, or less, than your Estimated Personal Budget.

- Your Personal Budget must be spent on achieving the things KASS agreed in your Support Plan. Your Personal Budget cannot be spent on anything that is illegal or would endanger you or another person.
- A Personal Budget does not count as income for tax or benefit purposes. It will not affect any benefits that you might receive. A Personal Budget is specifically to pay for your care and support; it is not a loan.
- If you think you need help to manage your support or the financial aspects, a suitable organisation could help you, a family member or friend or Kent Adult Social Services.

KASS has four options for managing a Personal Budget:

Option One: Direct Personal Budget

You can have your Personal Budget sent direct to a bank account set up to manage your Personal Budget, or to your 'Kent Card'. This is called a Direct Payment. You can use this money to organise, buy and manage your agreed support.

Option Two: Administered Personal Budget

You can organise and manage your agreed support yourself but ask someone else to manage your Personal Budget money for you. This could be KASS or an independent organisation.

Option Three: Managed Personal Budget

KASS can organise, buy and manage your agreed support and manage the Personal Budget for you.

Option Four: Combination Personal Budget

You may choose to use a combination of the previous three options. KASS will discuss this with you.

NOTE: The Kent Card is a Chip and PIN VISA card. KCC will load your Personal Budget money onto the card. You can use the card to pay for services either face to face using your PIN number, over the internet, or on the telephone. The Client Money Service (CMS) is available to allow people to manage their support, without having to manage the money.

The Direct Payments Process in Brief:

Contact: KENT CONTACT & ASSESSMENT SERVICES (KASS) - **08458 247100**

Short-term "enablement" service ie less than 6 weeks: usually free to receive

Signposting to other services

Assessment of Needs and Financial Status

Create a Support Plan *(What you hope to achieve and want help with)*

Estimated Personal Budget

ie if eligible for ongoing community-based service & finances from KASS to pay for it

IF: -Have care needs costing over £320 per week
 -Receive DLA (High Care rate)
 -Aged over 16 & under 65
Can also apply to ILF to top up DPs
NB Takes 12 weeks, reviewed 2 yearly

"Help" can be equipment or practical help for such things as care, social activities, cooking, shopping, employment

KASS approval of Support Plan - Actual Personal Budget

NB Public money: detailed records needed & separate bank account or Kent card (Chip and PIN Visa)
 This can be managed in four ways...

DIRECT
 (Personally)
 Full control, choice & independence
 BUT must also be an employer

Personally, but administered with help ie KASS, Friend / family, independent broker: control & choice over who employed but no responsibility for records

By KASS & they employ carers: less personal control. KASS is employer & no responsibility for records

A combination of these: can tailor it to the individual

NB: KASSs Aims: - Restore confidence
 - Promote independence
 - Reduce need for long-term care
 - ENABLEMENT (Not necessarily to do it yourself but to get the help required to do it)

Notes re DPs:
 - Separate from benefits, but contribution may be required
 - Not taxable or treated as income
 - Are specifically to pay for care

APPENDIX 1 – INDEPENDENT LIVING

Dave W Morris – Founding Director of Independent Living Alternatives described independent living thus:

“Disabled people have an inalienable right to independent living. It is often not understood what this means: It is about having more than an accessible environment and basic physical needs provided for; it is about a right to live spontaneously; a right to go to the toilet when you want to; a right to go to work or to study where and when you want to; a right to economic equality; a right to leisure; a right to express your sexuality; a right to determine your own lifestyle; a right to develop hopes and aspirations; a right to be accepted as a full and active member of the community; a right to positively promote our difference as disabled people, but not to have to think of the consequences every hour of the day. In essence, independent living is a misnomer: as disabled people we should be able to just think about living as anybody else”.

Independent Living.

This is the term used by disabled people to sum up their expectation of access to the opportunities enjoyed by their non-disabled peers. It describes the political aspiration for the inclusion of disabled people in society and the practical choices being looked for to enable this. This term also includes older disabled people and people in residential establishments of any age.

Independent Living and Disabled People.

Most people would define independence in terms of those activities someone is physically able to carry out for themselves. Following this line of reasoning, Independent Living would thus probably be explained in terms of the ability to provide for one’s own basic physical and intellectual needs on a day to day basis. Thus one of the ways disabled people and non-disabled people are defined is via notions of dependency. In many people’s view, to be disabled is to be dependent on others or to have choice compromised.

The trouble with such a widely accepted viewpoint is that it omits to recognise that human beings are social animals and that we are all inter-dependent on each other for many of our needs. Those people with the financial ability to do so might choose to employ someone to do many of life's everyday chores, like washing, cooking and cleaning, but in such a scenario they are still considered to be independent and not regarded as dependent on others.

Independent Living means something very different to disabled people. It is no longer defined in terms of what activities the individual can or cannot do for themselves, but is about having control over the resources that enable us to exert influence, choice and control over every aspect of our life.

It has evolved into a world-wide philosophy, since its origins in Berkeley, California in the early 1970s. Some seriously disabled students at UCLA rebelled against the inflexible and impractical arrangements provided to meet their care needs and demanded control of the resources to arrange these for themselves.

This led to the establishment of the original Centre for Independent Living and the beginning of a worldwide movement for change, led by disabled people themselves. It is a grass roots movement, which responds to the wishes and aspirations in disabled people's endeavours for an inclusive society.

In the UK, the Independent Living movement continues to grow. There is a clear move towards a greater degree of control, by organisations of disabled people, of resources and more and more Centres for Independent Living (CIL's) are being established.

2002 saw the establishment of a Centre for Independent Living in Kent, based at the Red Cross building in College Road, Maidstone.

APPENDIX 2 - DISABLED PEOPLE

The term 'disabled people' is based on the definition of disability used in the Disability Discrimination Act (DDA) 1995 (as amended by the DDA 2005). This applies to a wide range of disabilities including long-term health conditions.

The DDA 2005 covers people with a variety of impairments such as:

- learning disabilities.
- mental health conditions.
- mobility impairments.
- blind and partially-sighted people.
- deaf and hearing-impaired people; and
- progressive long-term health conditions such as multiple sclerosis and HIV.

It also includes:

- people with hidden impairments, for example people with long-term health conditions such as diabetes; and
- people who do not consider themselves to be disabled such as some older people with acquired visual or hearing impairments.

APPENDIX 3 - CENTRES FOR INDEPENDENT LIVING

CIL's are grass roots organisations run and controlled by disabled people.

Their aims are to assist disabled people take control over their lives and achieve full participation in society. There are currently 22 fully constituted CIL's with another 15 local disability organisations either providing a similar role or working towards becoming a CIL. For most, their main activity and source of income is running support schemes to enable disabled people to use Direct Payments. Such schemes involve:

- advice and information;
- advocacy and peer support;
- assistance with recruiting and employing Personal Assistants (PAs);
- a payroll service;

- a register of PAs; and
- training of PAs;
- running projects encouraging take-up of direct payments amongst marginalised groups;
- providing disability equality training;
- carrying out consumer audits of services.

Source: Improving the Life Chances of Disabled People January 2005.

APPENDIX 4 - THE TWELVE BASIC NEEDS

In Britain the disability movement has set about trying to define the necessary elements that need to be in place in order for Independent Living to be successful for disabled people. These were originally defined by Derbyshire Coalition of Disabled People, and became known as:

The Seven Basic Needs

- Information.
- Peer Counselling / support.
- Housing.
- Technology.
- Personal Assistance.
- Transport.
- Access.

These seven basic needs were then widened further still by Hampshire Coalition of Disabled People to include:

- Advocacy.
- Employment.
- Education.
- Income / Benefits.
- Appropriate & Accessible Health Care Provision.

The Independent Living movement world-wide has made significant advances in recent years, as increasing numbers of governments have accepted the arguments and are introducing policies designed to increase opportunities for independent living for disabled people.

A major success of the Independent Living movement in this country was the introduction of legislation to legalise Direct Payments, which can greatly increase the levels of choice and control available to disabled people.

We strongly believe that CiLK has the necessary skills and commitment to champion Direct Payments to people living in Kent. Thus enabling those who wish to do so gain control of their own 'care' requirements, with the necessary support and facilities.

Whilst we have a government publicly committed to social justice and inclusion for all, yet still supporting the principle of charging disabled people for essential personal assistance, we realise the battle for true equality has only just begun.

The Centre for Independent Living Kent Ltd would like to thank The Big Lottery for funding our unique mobile service and allowing us to produce this guide.

Ashford Gateway
Disability Information Services Kent (DISK)
European Year of Disabled People
Independence and Access Matters (*Iam*) 31st Dec 06
Julie Rose Stadium
Kent Action for Respite Care
Kent Adult Social Services
Kent Highway Services
Lloyds TSB Foundations
National Centre for Independent Living (NCIL)
Paladin Press
British Red Cross Maidstone
SCOPE
Southampton Centre for Independent Living
The Henry Smith Charity
Wheelchair Users Group

We would like to thank the organisations listed above for their help and support. Finally, special thanks to our staff, volunteers, members and individuals who have supported us with their valuable time.

CiILK

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