

The Centre for Independent Living in Glasgow Second Annual Report 1997-1998

CHAIRPERSON'S REPORT

Welcome to the Centre for Independent Living in Glasgow's Annual Report for 1997/98. This year will mark our 3rd anniversary of becoming a registered company. It is not my intention in this report to comment on all that has happened in the past year. The Manager and his staff are better equipped, as you will see in their reports, to do this for themselves.

There have been changes through the year to the Board of Directors. Barbara Clayton resigned in October because she was moving back to Edinburgh. Barbara was Vice-chair and the amount of work she did for CILiG from its conception was immense. Desmond McCaffrey also decided that he wanted to spread his wings in other directions, and he too left the Board. We wish Barbara and Des every success for the future.

In October we were all shocked at the sudden death of our colleague and friend, Valerie Bonel. Valerie had been with us from the very beginning and her life style, her sense of fun and adventurous spirit, was an inspiration to us all.

Valerie was a fine example of how empowering independent living can be for disabled people. She is sadly missed.

In February, Helen Cogan, our Training Co-ordinator, moved on to pastures new. I thank Helen for the sterling work she did for us and wish her every success in her new career.

Life, as they say, must go on and changes do happen, whether planned or unplanned. It therefore gives me great pleasure to thank Marianne Scobie, Lois Brooks and Kevin Paterson who were all co-opted onto the Board of Directors during the year. They brought in fresh ideas and gave new impetus to the organisation. Their contribution is much appreciated. Also, we welcomed Donald Anderson who joined us as Training Co-ordinator in June and I am sure his wide skills and expertise will be of great value to CILiG.

I can remember quite clearly stating last year how CILiG was visibly

evolving as a potent force for the empowerment of disabled people in Glasgow. Well, things have not changed!.

Ask what has been happening locally, and often nationally, and you will find CILiG is at the fore, leading the charge on many a front on the issues affecting disabled people.

By way of example, we have been involved in: GCC's direct payments consultation; the Accessible Transport Strategy Project; a further proposal for a user-led housing service; a joint bid to develop a National Disability Information Service; the Scottish Personal Assistance Employers Network, to name but a few.

I think this shows how resilient our organisation is considering the fact that we, like many others this year, have been affected by the budget cuts. We are weathering the storm through some difficult times and it's not over yet.

CILiG's future has to be firmly established once and for all. We are confident we can secure this future and are working to this end. The support and services we provide on Independent Living issues is fast becoming the recognised framework which Social Work Departments will require for their clients, particularly those who wish to live independently. And we are the experts in providing that support.

On a personal level, of the numerous issues I have been involved in this year, I have taken most pleasure in becoming the first disabled person to be co-opted to the Glasgow City Council Equality Committee through my involvement with the Disability Working Group. This is a major step forward for disabled people to be involved in the policy making process of local government on the issues which affect our lives. It is early days yet, but I believe we are making good progress.

To round up, I say, thanks again to all the members of staff. Thanks, again, to past and present serving members of the Board who have helped me in my duties. You have all worked hard. You have much to be proud of and a lot to look forward to. Finally, to the most important people connected with CILiG, its members, I thank you for your valued and, I hope, continued support.

Peter Brawley

Chairperson BOARD OF DIRECTORS

CILiG is managed by a Board of Directors which determines the policies and direction of the CIL, ensures its funding and works closely with staff.

During 1997/98, 3 Directors departed the Board and 3 were appointed.

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| Chairperson | Peter Brawley |
| Vice-chairperson | Barbara Clayton (resigned 24.10.97) Jim McSharry |
| Treasurer | Maureen Cresswell-Boyle |
| Member Directors | Valerie Bonel (deceased 26.10.97) Lois Brooks (appointed 13.11.97) Des McCaffery (resigned 12.11.97) Maureen Messer Christine McLeod Kevin Paterson (appointed 13.11.97) Lesley Paterson Marianne Scobie (appointed 13.11.97) |
| Appointed Directors | Jim Woodward Louise Fyfe Bill Perry |

CENTRE MANAGER'S REPORT

The past year has been one of mixed fortunes for the CIL. On the one hand I am pleased to say that our reputation as an organisation able to deliver professional and effective services continues to grow. I have lost count of the number of approaches we received throughout the year to become involved in projects, steering groups and campaigns both locally and nationally - many of them worthy of support. The simple truth is that we cannot become involved in everything and we have had to prioritise in using our energies and resources.

Especially pleasing has been the support and encouragement we have been able to give to numerous groups of disabled people in other parts of the UK who are trying to set up their own CILs. Several groups have visited CILiG and have said they returned home with renewed enthusiasm and greater ambitions.

On the other, we have experienced real difficulties in securing funding, not just for new initiatives such as a Housing Service, but simply to keep pace with rising costs. Within this financial climate it has not been possible to realise the continued developments we had hoped for, particularly in supporting increased numbers of disabled people to set up personal assistance packages.

Clearly, the Social Work Department has experienced unprecedented turbulence in its own funding and organisation. However, we sincerely hope for a period of stability and a more productive partnership with the Department in future months.

A further frustration had been the delay in the implementation of direct payments in Glasgow. CILiG, along with the PA Employers Support Group, played a key role in planning and running the major consultation exercise on direct payments which the Social Work Department conducted last autumn. The target date for implementation is now likely to be April 1999. During this period we have had to rethink how we can best use our expertise and limited resources given that few new independent living packages are being funded. As a result we have changed our training programme for PA Employers to focus on shorter courses for existing employers and we have put proposals to the Department for a wider range of support options once direct payments are in place.

Despite a freeze on the Independent Living Service budget, we have continued to provide detailed and ongoing support to PA Employers in the city. We have also been able to consolidate the Emergency Back-up Service (EBUS) with over 200 bookings made through the service in 1997/98 and 33 PAs recruited. As far as we are aware, the EBUS remains one of the few services of its type in the UK.

As reported elsewhere in this Annual Report, the Information Service has had another busy year. We have been especially proud of the first rate work carried out by Information and Development Co-ordinator, Grant

Carson, on supporting people who have been victims of the Benefits Integrity Project. Grant's 'Survival Guide' has acquired a strong reputation nationally for being the best of its kind and has been much in demand. Repeated representations to Government by disabled people's organisations including CILiG and others may hopefully mean we have now seen the worst of this damaging and unjust programme.

In February, we bid a fond farewell to our Training Co-ordinator, Helen Cogan, who did so much to build a firm foundation for our Training Service. Taking up the reins is Donald Anderson, returning to Glasgow after an extended sabbatical in foreign parts (eg Moray) lasting some 24 years! Donald has a wealth of experience and skills to draw on and I am confident the Training Service will grow from strength to strength in his hands.

Two major projects were undertaken during the year. The Accessible Transport Strategy Project has been managed by CILiG on behalf of the Equality Committee's Disability Working Group. The project set out to devise a strategy for working towards an accessible public transport system in Glasgow in a way which fully involved and empowered disabled people. The completed strategy document will be a vital tool in enabling disabled people to participate in this process on equal terms.

The Participative Evaluation Project has been developing tools for evaluating CILiG's services - again by involving service users from the word go. Users of CILiG's services have been working with CIL staff and consultants from the Policy Studies Institute to agree what the key measures of quality should be and also to become involved in doing the research. Unfortunately, the project has been delayed in recent months by unforeseen circumstances, but it is hoped to complete the research during the autumn of 1998.

An important but often unrecognised part of CILiG's work is the support we have been able to give other organisations. During the year we have made significant contributions towards the establishment of a number of new user-led organisations including: the Scottish Personal Assistant Employers Network; the Glasgow Access Panel; and the new Glasgow-wide campaigning organisation of disabled people.

We look forward to these organisations giving disabled people in Scotland and in Glasgow a stronger and more unified voice.

The coming year does not appear to offer any obvious comfort on the financial front. Indeed, the financial climate seems as hard to predict as the weather at the present time. However, we must continue to press even harder for disabled people to get a fair share of resources in order to start to address the inequalities we face in society. There are many challenges in the year ahead; implementing the transport strategy, getting funding for new initiatives and hopefully developing new support options are just some of them.

In conclusion I would like to pay tribute to the hard work and commitment of CILiG's staff, Directors and all the members and colleagues who have supported our endeavours to work effectively on behalf of disabled people in Glasgow.

Etienne d'Aboville

Centre Manager

Who's Who at the Centre for Independent Living in Glasgow?

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| Centre Manager | Etienne d'Aboville |
| Administrator | Sue Domminney |
| Co-ordinator Information & Development | Grant Carson |
| Co-ordinator Training | Donald Anderson |
| Co-ordinator Personal Assistance Services | Maureen McPeak |
| Clerical Workers | Margaret Sanders Carol Smith Christine Smith |
| Caretakers/Personal Assistants | John Stoddard Ken Walton |
| Cleaner | Rena Daley |

PERSONAL ASSISTANCE SERVICES

During the past year, demand for the Personal Assistance Services has continued to increase. A major disappointment, however, was the news that no new money was to be made available this year to disabled people in Glasgow who wished to set up their own independent living packages. Instead, people have had to accept direct services in lieu of the local authority contribution before the Independent Living Fund can be approached for additional funding. This does severely limit the element of control they have over their package. However, despite this setback, a lot has been achieved.

Emergency Back-up Service

The Emergency Back-up Service (EBUS) has gone from strength to strength. In all, 201 booking requests were received during the year and evaluation by users has been overwhelmingly positive.

“You get a great service from CILiG, the staff are so friendly and relaxed, the whole place has a great atmosphere. All the PAs I have had have been excellent”.
Marie Mohan

It has been encouraging to get such positive feedback, particularly in view of the difficulties of providing a 24 hour, 365 day a year service. The challenge has been to provide a service which ensures that real control lies with disabled people, but which is also workable from an administrative point of view. We feel we have been able to achieve this by working in partnership to develop a service based on the experience of employers and actively involving them in evaluation.

” We know you will always do your very best for us, even at short notice, we are really very happy with the service you provide”.
Betty Sweeney

Recruitment

During the year, 33 Personal Assistants were recruited from the Register by Personal Assistance Employers. A new development has been disabled students using their Disabled Students Allowance to recruit PAs.

Also, a number of people who are unhappy with increased home-care charges have also been choosing to employ PAs using their Disability Living Allowance care component.

One to One Advocacy

Although there is currently no new money to set up Independent Living packages, CILiG has continued to encourage people to apply for funding if they meet the criteria. PA Services Co-ordinator, Maureen McPeak has supported approximately 40 disabled people to prepare for Community Care Assessments or recruit new PAs during the year. Maureen says *'I am now even more convinced that it is vital that disabled people get support and advice prior to an assessment so that they can feel more in control of the entire process.'* Hopes for the future are that CILiG can establish an Independent Advocacy Service that would enable us to provide this level of support to any disabled person in Glasgow, as and when they need it. Within the present available resources, it is felt to be better to provide a quality service to a smaller number of people, rather than a superficial service to many.

Personal Assistant Employers Support Group

CILiG has continued to provide support for the Personal Assistant Employers Support Group throughout the year. The Group is now well established and has successfully secured funding from the City Council for organisational and meeting costs. We look forward to working in partnership with the PAESG during the coming year on issues such as:

- a Code of Good Practice for Personal Assistant Employers
- an Arbitration Service to help resolve disputes between Employers and PAs
- direct payments
- planning and developing Independent Living Services in Glasgow

Personal Assistants

Although CILiG's main function is to support Personal Assistant Employers, we are sometimes called upon to provide information or advice to PAs on the Register. Often, this is because working as a PA is a new area of work for most people. CILiG therefore convened a meeting for all the PAs on the Register to explore different ways in which PAs might access appropriate support. PAs felt that a PA Support Group of some kind would be helpful and that this could also liaise with the Employers Support Group. So, there may be some exciting developments in the future.

"I really enjoy being on the personal assistance register. I get to meet lots of different people. The tasks I am asked to undertake are varied and interesting. I find working as a PA valuable experience." David Ewing

PA Employer's Support Group

The year since the last CILiG AGM has been quite a busy one for the PA Employer's Support Group. We have now become a properly constituted group and our Constitution was sent to the Inland Revenue with an application for charitable status. Unfortunately, the application was rejected but we plan to lodge an appeal.

Since becoming properly constituted, we have submitted small grant applications to the various local councils in the Glasgow area to cover running costs and travel expenses to meetings at the CIL. One of these was successful and a grant of £2,600 has been awarded, from Glasgow City Council, for travel to meetings. Other up-and-coming courses include a CSV-organised series on writing funding applications, marketing and public speaking.

Our first year as a group saw the sad death of our Treasurer, Valerie Bonel. Her energy and drive will be sadly missed, both by the Committee and by the wider group of PA Employers.

Lastly, we would like to thank the CILiG for its continuing support, both financial (in the early stages of our formation) and moral, Madge Cocozza, our support worker, for her sterling efforts and work on our behalf and Etienne d'Aboville and his staff for their invaluable help and support. It is our hope and expectation that we can continue the work done thus far and be a forum for and advocate of the benefits of independent living and the Independent Living Movement.

William Murray

Vice-Chair

PA Employer's Support Group

TRAINING

This year has been a year of achievement for the Training Service. There was an increase in the number of courses organised and the range of training was extended to include Disability Equality Training and Training the Trainers.

Personal Assistant Employers

The PA Employers course covers all aspects of recruiting and working with PAs including Writing a Job Description, Interview Techniques, Training and Managing your PA, Good Employment Practices and Payroll Options. The two courses held during the year, one in Glasgow and one in Greenock, were attended by a total of 19 PA Employers.

“I would recommend this course to anyone who employs a PA or is thinking about it. It gave me the confidence to deal with the issues which arise when you employ PAs.”

Jane

Sorbie

In addition, training was organised for PA Employers on the following topics:

1. Managing your Package - The Paperwork.
2. The Inland Revenue's Simplified Deduction Scheme.
3. Committee Skills/Roles of a Committee.
4. A series of sessions covering - How to Write a Good Funding Application, Effective Meetings, Presentation Skills and Marketing.

The priority for the coming year will be to concentrate on training for existing PA Employers. The freeze on the Independent Living Services budget has severely limited the number of new packages being set up. Also, the present training course is run on two half-days a week for a period of 11 weeks and we recognise that this time commitment can be difficult to maintain. We are therefore looking at providing more short courses in a modular form.

Personal Assistants

In the past year a total of 15 two-day PA courses were held. Altogether, 121 people completed the course and, of these, 103 eventually joined the Register. We also provided additional training to a small number of PAs to meet the specific requirements of a number of Employers.

New PAs are always in demand and we will continue to run these courses throughout the coming year to meet the requirements of the Emergency Back-up Register.

Disability Equality and Other Training

A total of 20 Disability Equality Training courses were organised during the year in response to requests from voluntary groups, teachers, hospital staff and solicitors.

“The course was very enjoyable, helpful and informative about the work of a PA.”

Rhona Keerns

Although designed to meet each group’s individual requirements, the courses were designed around a basic framework of issues:

- Terminology and Language
- Defining Disability
- Medical and Social Models of Disability
- Disabling Barriers within Society
- Examples of Good and Bad Practice

During the year, CLiG staff also provided numerous training sessions or talks on a wide range of issues including direct payments, the Disability Discrimination Act, housing and welfare rights issues.

Feedback on DET courses has been very positive, the following are a sample

“Very informative, I would recommend this course to others.”

“Thank you for opening my eyes.”

“Excellent course, should be compulsory for all staff.”

“I am very glad I came today. I now feel more aware of the issues affecting disabled people in today’s society.”

Training the Trainers

The increasing number of requests for training highlighted the need for a pool of disabled people who could provide high quality training to an agreed standard.

In response to this need CILiG organised a training course for 13 people in October and November 1997. The course was delivered over 10 sessions under two main headings - Disability Issues and Training the Trainers. Both parts of the course were designed to increase confidence and knowledge of the issues and techniques available to trainers.

The pool of trainers will be an increasingly valuable resource in the future. It will ensure that, for instance, Disability Equality Training is carried out by disabled people to a high standard and in a way which is accountable to disabled people themselves.

INFORMATION SERVICES

CILiG continues to offer a comprehensive Information Service to clients. From April 1997 to March 1998 the Information Service responded to around **965** detailed enquiries.

Topics covered included:

- benefits/welfare rights
- housing
- independent living
- aids & equipment
- adaptations
- employment opportunities
- social / recreational activities

Welfare rights

The issue of welfare reform gave many disabled people cause for concern. Media reports of disabled people losing Disability Living Allowance due to the activities of the Benefit Integrity Project (BIP) created a large number of referrals.

BIP was launched in April 1997 and is a controversial ongoing investigation into the DLA entitlement of over 400,000 severely impaired disabled people. Since DLA is the gateway benefit for the Independent Living Fund this had potentially devastating consequences for clients of CILiG.

In response to repeated requests for help, the Information Service created the BIP Survival Guide (which includes information on BIP, DLA entitlement, standard letters to enable people to easily ask for reviews & appeals etc.) to inform and arm disabled people about their rights.

The Survival Guide proved to be very popular and LINK (ITV programme) paid CILiG £1,000 for producing it. A coalition of organisations including LINK, DIAL UK, and many others distributed in excess of 10,000 copies to disabled people across the UK.

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| <p>"I found the legal information in the BIP self-help Survival Guide invaluable. It enabled me to challenge the DSS decisions and persuade them to exclude me from their investigations".</p> <p>Mr. English</p> |
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Legal challenge

CILiG believes there is a chance that the actions of BIP are illegal, being an improper use of a discretionary power. A suitable test case has therefore been identified and an application has been made to the Scottish Legal Aid board to fund a judicial review.

Aids & equipment

A large number of enquiries continue to be received regarding independent living equipment. For example, recently, a client with cystic fibrosis asked for information on a new type of vibrating vest. Various contacts were made including the Cystic Fibrosis Trust, RADAR, Disabled Living Foundation and other organisations without success. Eventually, however, through the Chartered Society of Physiotherapists some information was forthcoming. The device costs over £12,000 and is only available in the USA. Apparently in the UK various physiotherapists have used a Black & Decker hammer drill fitted with a rubber suction cup for the same effect!

Housing advice

Housing is the cornerstone of independent living, without a user friendly accessible house disabled people cannot take advantage of any employment, educational, or recreational activities. The Housing factsheet continues to be one of the most popular, giving information on accessible accommodation providers in Glasgow. In addition, using innovative practice can make community care work to dramatically improve the quality of life for disabled people in Glasgow.

Housing advice - Case study.

The information service was contacted in November 1997 by "Michael", a 25 yr. old man living in an inaccessible house. He wished to have his own accommodation, which he could enter and leave without help in the east end of Glasgow. He was forced to investigate owner occupation due to the shortage of accessible housing available to rent in his chosen area. He found a house himself and placed a £50.00 deposit on it. It was after taking this initial step of initiative himself that he began to experience problems obtaining a mortgage and approached CILiG for help.

Obtaining a mortgage for someone on benefits, with no capital or savings is very difficult and usually proves to be impossible. However, after a

considerable amount of persuasion an application was approved by the Dunfermline Building Society for a 95% interest only mortgage. The mortgage was only possible because we put together a suitable funding / guarantor package in collaboration with The Thistle Foundation

After 8 months work raising money from various sources, Michael moved into his chosen property (2 bedrooms - a personal assistant/relative can stay when necessary) on the 12th of March 1998. Michael is now living happily in the area he was born in, where he has both relatives and friends for social support.

The total amount of money needed to enable Michael to enter owner occupation (cost of house, all fees, furniture, carpets, adaptations etc.) was £43,716. We believe that this was the first time in Scotland that such a package has been put together to enable someone on income support to move into owner occupation.

" My new cottage flat is a dream come true. Thanks for everything you have done, without your expertise and time it would not have been possible".

Michael