

# **PAINTING OUR PICTURE**

**A GUIDE TO THE DISABILITY FEDERATION OF IRELAND  
AFFILIATED ORGANISATIONS  
FOR PEOPLE WITH PHYSICAL OR SENSORY DISABILITIES  
OR WITH MENTAL HEALTH PROBLEMS**



**DISABILITY FEDERATION OF IRELAND**

**COMPILED AND EDITED BY  
JUDITH KIERNAN  
FOR DISABILITY FEDERATION OF IRELAND**

**MARCH 2000**

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## **ACKNOWLEDGEMENTS**

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The seed of this publication came from Roger Acton, then chief executive officer of Disability Federation of Ireland (DFI). The researcher wishes sincerely to thank Kieran Loughran of DFI who was always available to give advice and suggestions throughout the project, the DFI secretariat staff Averil Brennan and Noreen Woods who provided details of personal contacts and makes special mention of the involvement of the current CEO of DFI, John Dolan.

Judith Kiernan  
March 2000

## FOREWORD

Early last year, Disability Federation of Ireland (DFI) decided to undertake research into physical, sensory and mental health services provided through its affiliated organisations. The federation considered that it was still difficult to get a picture of the general state of development of these organisations, their ranges of services and other activities. The federation also observed that the recent, major strides forward in the learning disability voluntary services' sector were facilitated and underpinned by an understanding of the opportunities and challenges facing that sector. In the light of these considerations, the federation commissioned the present research.

This was the first attempt at such a project among a large number of organisations, (56 in all), with a diversity of objectives, approaches and styles. It is not surprising that the research prompts as many questions as it answers. In this sense, ultimately, we may have learned as much from the process, as from the final product.

Disability, with its ever-unfolding ramifications, constantly challenges all of us within the sector and in society at large. As a society, we are obliged to respond to the outcomes of improved medical technology, to the social costs of our increased life span, to changing attitudes of people with disabilities towards disability, to the genesis and evolution of a social rights perspective which emphasises societal participation for all. As one sector within the framework of civil society, we seek to reflect and to respond to these societal expectations and evolutions.

All of the organisations described here have been, and continue to be, affected by the prevailing social and political ethos. From the time of their foundation, this may have ranged from attempts to "relieve the suffering of the incurable", through to the development of representative groups of similarly disabled people seeking inclusion, to the institution of service provision and advocacy groups for small numbers of people with rare medical conditions. All of these historical influences are now overlaid by the sea-changes of disability rights and social inclusion which are gradually beginning to reshape and refocus the sector, and society, as a whole.

Voluntary organisations working for and with people with disabilities have no universal template. We must see this as one of the vibrant strengths of the sector - that each individual or family whose lives are affected by disability will seek, and are entitled to, unique responses to their needs and expectations. This guide gives us an insight into the wide range of ways in which these organisations respond to individuals and groups, not only through support-focussed services, but also through a wide range of information, advocacy and representation roles. In many ways, the picture painted in this guide is a testament to the role of voluntary organisations as one skein in the thread of representative and participatory democracy.

Many national, regional and sectoral issues have surfaced within this project. These range from broad questions about the reflexive influence of social change on voluntary organisations, to questions about the best mechanisms to ensure quality and standards of service delivery. For present purposes, we may look in brief at some of the main issues raised by and through this compilation and some of the questions that they pose.

**VOLUNTARY ORGANISATIONS BOTH REFLECT AND ASSIST IN SHAPING THE CURRENT SOCIAL CLIMATE.** How should we respond to a time of change for and within the sector? How do we develop new ways to operate, to respond to and enable change?

**VOLUNTARY REPRESENTATIVE ORGANISATIONS HAVE LEGITIMATE ROLES IN A DEMOCRATIC SOCIETY.** What are the scope and limits of these roles? How can these be put into practice? What can enable or hinder these roles? To what extent is it legitimate for the sector, and each of the organisations within it, to expect State funding for these roles?

**SERVICE POLICY DESIGN AND IMPLEMENTATION MUST ENSURE QUALITY, COMPREHENSIVE AND EQUITABLE NATIONAL SERVICE PROVISION AND DELIVERY.** To achieve this goal, 3 distinct groups, namely the State, the voluntary sector, and its client groups and individual service users, must be included in decision-making. Can we construct an interface between statutory agencies, voluntary providers and service users that is conducive to the improvement of services in every part of the country?

**VOLUNTARY ORGANISATIONS ARE SOMETIMES THE PRIMARY OR KEY AGENCIES IN THE DEVELOPMENT OF CERTAIN TYPES OF SERVICES.** What should be the parameters for the establishment of the need for, or the right to, these services? Can innovative, pilot or action research projects provide useful lessons and avenues forward? Are there ways of ensuring best practice for services at a national level?

**STATUTORY FUNDING OF SERVICES PROVIDED BY THE VOLUNTARY SECTOR IS PARTIAL AND OFTEN LESS THAN TRANSPARENT IN ITS OPERATION.** How can this unsatisfactory present situation be addressed to ensure fairness? How may standards and procedures be set and monitored? How may we use our experience to modify policy and service delivery?

**MANY VOLUNTARY ORGANISATIONS HAVE A CLOSE AND DIRECT RELATIONSHIP WITH THEIR SERVICE USERS.** What lessons may be drawn from the organic way in which organisations tend to develop services as a distinct response to the individual or family?

**SOME ORGANISATIONS ARE UNDER CONSIDERABLE ONGOING PRESSURES, IN RELATION TO FUNDING, TO STAFFING, TO QUALITY ASSURANCE ISSUES AND TO SERVICE MAINTENANCE AND DEVELOPMENT.** How may we respond to the problems and fears of voluntary organisations? Can we assist organisations to develop their management and decision-making functions? How can we enable organisations to develop proactive, interactional styles of management and communication?

**THE SCOPE FOR COOPERATION AND COORDINATION BETWEEN VOLUNTARY AGENCIES AND BETWEEN THESE AGENCIES AND THE STATE IS LARGELY UNTESTED.**

This guide gives a number of benchmark examples. What good practice or service innovations may be generalised or modified to local circumstances?

Some of these issues have been on the agenda for some time. At this stage a continuing piecemeal approach to finding solutions seems not only inappropriate but counterproductive. DFI wishes to play a proactive role in both the national and sectoral debate about the voluntary service sector. This guide is one source of information and inquiry. It is a reflection of the state of the sector at this juncture. We must all take an uncompromising look at its present status and move forward with the overriding aim to improve the lives, the opportunities and participation of people with physical or sensory disability or with mental health problems.

One issue is now unequivocal: the term *service provider* as a description of the voluntary disability sector is neither accurate nor helpful. Voluntary disability organisations are not merely conduits for the delivery of services, through funding provided by the State or other sources. Fully 83.9% of the organisations described in this guide engage in advocacy. Almost 93.0% provide a range of information and advice services. Each organisation seeks to develop its services in response to the views, needs and expectations of the users. We must strongly articulate our roles and our values. Otherwise, we may continue to be painted into someone else's picture.

John Dolan

March 2000



# **ABODE HOSTEL AND DAY CENTRE**

## **DOORWAY TO LIFE**

**Address:** Mahon  
Cork  
Co. Cork

**Tel:** Day centre (021) 357606  
**Tel:** Hostel (021) 357119

**Manager:** Claire Brazil

### **INTRODUCING ABODE HOSTEL AND DAY CENTRE**

Abode Hostel and Day Centre was established in 1984 to provide services for people with disabilities and to empower clients to live the life of their choice to its fullest potential. In the past number of years, the centre has developed Doorway to Life's level one independent living programme and has provided additional weekend respite breaks.

Abode's main ongoing problem is in securing financial assistance to provide and develop services. In particular, it has problems finding and funding housing and PA services for clients who have completed the independent living programme. Abode wishes to increase its staff complement; specifically, the day centre wishes to secure the services of an occupational therapist. Abode finds that the lack of accessible public transport hampers its ability to provide services.

### **MEMBERSHIP AND BOARD STRUCTURE**

Abode is not a membership-based organisation. It is a company limited by guarantee. Its charity number is CHY: 6876. The board consists of 12 directors, with a rotation every two years and with 12 meetings per annum.

### **INCOME AND EXPENDITURE**

In 1998, Abode obtained funding from the Southern Health Board and the Department of Health and Children. The FAS-funded CE scheme in operation at Abode is worth approximately £19,000. In 1999, the Abode independent living programme obtained European Social Fund (ESF) assistance. Abode obtains fees from clients and also accepts donations. It has flag days in April and August each year and hosts charity events. Total directly employed wage costs were £193,213 in 1998.

### **STAFF**

Abode has 18 staff, 4 of whom are administrative, 5 staff are CE workers and 3 are part-time. 8 staff members have qualifications. Abode has no volunteers.

### *CE scheme*

The CE scheme is of value in that it complements the work of full-time staff in the provision of services. CE workers have had a 40% success rate in obtaining mainstream employment.

### *Training, monitoring and evaluation procedures*

Abode operates accredited and other in-house induction and training programmes for staff and CE workers and sees value in developing these further. Abode has written safety procedures and internal reporting mechanisms. Abode undertook an independent service-user evaluation in 1996.

### **PREMISES**

The hostel and day centre are custom built and completely accessible. Administrative staff have dedicated computer facilities. There are no drop-in facilities and no meeting rooms. Abode also has a rented independent living unit.

## **SERVICES**

### **INFORMATION SERVICES**

Abode is not an information service provider. It has promotional videos and a brochure. It publishes an annual report.

### **MEDICAL/NURSING /THERAPEUTIC SERVICES**

A nurse is on duty each night in the hostel. Abode would like to have the services of a physiotherapist and occupational therapist on the site. Abode offers rehabilitative day activity.

### **SUPPORT SERVICES**

#### *Respite services*

Abode offers short-term residential respite breaks.

### **RECREATION SERVICES**

The Abode day centre provides daily recreation activities.

#### *Holidays*

Abode offers holiday accommodation. Doorway to Life provides holidays for people with disabilities.

### **VOCATIONAL/EMPLOYMENT SERVICES**

Abode is setting up a level one independent living programme which includes a vocational training placement. Abode provides a placement each year for a student undertaking the National Certificate/Diploma in Social Studies. Abode also provides a transition year placement for a secondary school student.

**HOUSING SERVICES**

The Abode hostel is a short-term respite facility. Abode provides accessible rented accommodation for trainees on the independent living programme. Abode is critical of the lack of suitable housing for clients who have completed the programme.

**INDEPENDENCE SERVICES**

Abode has an independent living programme for people with physical disabilities. Abode has difficulty in sourcing funds to employ personal assistants (PAs) for clients who have completed the programme.

# **ACTION FOR MOBILITY**

Address: Sean Farrell,  
8 Elizabeth Street  
Dublin 3

Tel: 8378633 (after 6.00pm)

Also Jim Condon  
42 Shannid Road  
Harold's Cross  
Dublin 6

Tel: 4922568

E-mail: [condonjj@iol.ie](mailto:condonjj@iol.ie)

## **INTRODUCING ACTION FOR MOBILITY**

Action for Mobility was founded in 1987. It operates on a volunteer basis and has no paid staff. All members have equal participation in the ongoing development of the ethos and structure of the group. It is a campaigning group which seeks full social integration of people with physical disabilities. It has an active education and awareness programme. It advocates a fully integrated, accessible public transport system. While it is not a service provider, it organises events for members.

Action for Mobility identifies the main issue confronting the group as the importance of recruitment of, and training for, members. It points to the core demands of members for access to public transport, to education and to work opportunities.

## **MEMBERSHIP AND BOARD STRUCTURE**

Action for Mobility has a membership of about 70, located in the Dublin area. Activities are typically community-based, so nonmembers are also included. The committee has 9 members who are elected annually at the Annual general meeting (AGM) and holds about 9 meetings per annum.

## **INCOME AND EXPENDITURE**

Action for Mobility obtains about £10,000 in lottery funding through the Department of Health and Children every 3 years. It also raises £2,500 annually through quizzes, raffles etc. It has an annual quiz in November. It obtained a People in Need grant of £1,000 to assist with the publication of its 10-year review.

### *Training procedures*

Members attend courses from time to time, e.g. with the National Social Services Board (NSSB). Action for Mobility runs in-house induction and officer training programmes. It recruits members by way of publicity, leaflet drops and radio advertisement.

### **PREMISES**

Action for Mobility rents a disabled accessible meeting room when necessary.

## **SERVICES**

### **INFORMATION SERVICES**

Action for Mobility seeks media publicity for its activities and perspectives. It publishes a newsletter 3 times a year for members. In 1990, it published a report *Access for Disabled People in Dublin*. In 1997, it published a 10-year review of its activities. Members visit schools and community groups to provide information programmes to counteract existing negative attitudes to people with disabilities.

### **SUPPORT SERVICES**

#### *Financial support*

Action for Mobility provides small grants (up to £40) to assist members with course fees for adult education.

### **RECREATION SERVICES**

Action for Mobility functions, in part, as a social club. Members arrange a monthly programme of events. They organise 3/4 holidays per year. The club also has ongoing participation in mainstream social events such as concerts, pubs and football matches.

### **TRAINING SERVICES**

Action for Mobility is planning a 1-day conference in relation to training and job opportunities in 2000.

### **ADVOCACY SERVICES**

Action for Mobility lobbies politicians, particularly on the issue of accessible public transport. It has organised seminars on the topic of transport with European Union election candidates.

**AHEAD**  
**ASSOCIATION FOR HIGHER EDUCATION**  
**ACCESS AND DISABILITY**

Address: Newman House  
86 St. Stephen's Green  
Dublin 2

Tel: (01) 4752386

Fax: (01) 4752387

E-mail: [ahead@aonad.iol.ie](mailto:ahead@aonad.iol.ie)

Website: [www.ahead.ie](http://www.ahead.ie)

Director: Caroline McGrath  
Employment coordinator: Mary Ruane  
Research and development officer: Pat Hoey  
Administrator: Pauline Ryder

#### **INTRODUCING AHEAD**

AHEAD was formed in 1989 and is an independent voluntary organisation which promotes improved access for people with disabilities to higher education in the island of Ireland. It seeks to achieve its aim through research and policy development. It aims to inform and develop national policy on the education of students with disabilities and the employment of disabled graduates. It acts in partnership with the Higher Education Authority (HEA), the statutory body responsible for the funding of universities and designated third-level institutions, with higher education institutions and with other educational bodies. It campaigns to improve access to, and increased participation of students with disabilities in, third level education in Ireland.

AHEAD's main achievements to date have been the development of a recognition of its role and input within the higher education establishment, its growing corpus of research on a wide range of issues concerning disability and higher education and the gradual changes in admission and support policies in the third level education courses. AHEAD has completed its most recent 5-year plan and seeks now to establish a new set of objectives for the next period.

#### **MEMBERSHIP AND BOARD STRUCTURE**

Membership is open to all of the institutes of higher education, to students with a disability, to disability interest or advocacy groups and to any interested individual. AHEAD has no regional or branch network.

AHEAD is a company limited by guarantee. Its charity number is CHY: 9999. At the annual general meeting (AGM), all in attendance elect a council which comprises 2 representatives of

each of the institutes of higher education and each individual member. This council body, in turn, nominates ordinary members to the board, half of whom are from the institutes of higher education and half are people with disabilities. Rotation of board membership occurs every year, while honorary officers are appointed for 3 years, with no upper age limit. This board meets 4-6 times per year. The executive board comprises 10 members and 3 honorary officers. This entire structure is under review.

#### **INCOME AND EXPENDITURE**

AHEAD is core-funded by the HEA. In 1998, HEA funding was £75,000. In addition, AHEAD obtained £91,370 through EU European Social Fund (ESF) Horizon funding. In the past, AHEAD has received other EU funding including from the Leonardo scheme. Of significant immediate future concern to AHEAD is that decreased EU funding may significantly curtail its core action research programme. AHEAD has also received funding from the Industrial Development Authority (IDA). Two CE workers are funded through FAS. Other sources of funding include membership subscriptions. AHEAD undertakes no fundraising.

#### *Expenditure*

AHEAD spent £215,795 on all of its activities in 1998. This included £88,739 on salaries, £10,936 on externally contracted research work, £16,285 on training costs linked to the graduates in further training (GIFT) programme, £46,991 on a secondary level education survey and £11,455 on a EU Socrates mobility project.

#### **STAFF**

AHEAD employs 3.5 full-time staff. All of the staff have necessary or relevant qualifications. In addition, AHEAD has begun to participate in the FAS CE programme and has 2 CE workers. AHEAD is consistently supported through inputs from people working in higher education, including members of the executive, who are not paid by AHEAD for their assistance.

#### *Training, monitoring and evaluation procedures*

AHEAD operates no accredited training programmes for staff and does not see necessary benefits to such a development. AHEAD staff are facilitated to attend external courses relevant to their work. AHEAD operates in-house training programmes for staff and has induction periods for new staff. AHEAD's activities have been both independently and internally reviewed.

#### **PREMISES**

AHEAD has offices on the second floor of a large building, with no disabled access and no drop-in facilities. AHEAD staff will meet people outside the office.

## SERVICES

AHEAD is a policy development agency, which seeks, through its research programme, to provide an independent critique of existing approaches and make recommendations for potential improvements to the Department of Education and Science, the Higher Education Authority (HEA) and the various institutes of higher education. AHEAD does not directly assist people with disabilities wishing to attend or attending third level institutions and therefore provides no education, support, vocational, employment or personal advocacy services.

### INFORMATION SERVICES

#### *General public policy information*

AHEAD seeks to promote dialogue and debate on the topic of disability access to third level education. AHEAD staff attend conferences and gives presentations. The organisation presents submissions, e.g. to the Commission on the Points System, the Department of Equality and Law Reform, the Department of Social, Community and Family Affairs and the Industrial Development Authority (IDA). It has also presented reports to the EU Commission. It produced *Legislation, disability and higher education (1995)*, comparing legal provision in several European countries.

#### *Institutes of higher education*

AHEAD provides an information service to all of the institutes of higher education. This focuses on best practice in relation to admissions and support policies to enable people with disabilities to attend and to succeed at third level. AHEAD raises awareness of disability issues among staff in third level institutions in areas such as admissions and examinations policies, dyslexia, course structures, career options, development of study skills and support programmes. AHEAD has published a number of reports including *Alternative access routes to third level education in the Republic of Ireland - findings of an admissions survey of the third level sector (1998)*. Another AHEAD publication *Third level options: disability provisions in higher education in Ireland (1994)* reports on the results of a survey on the provision for students with disabilities in third level colleges. *Examination facilities and arrangements for candidates with disabilities (1994)* describes reasonable provisions for candidates with disabilities during examinations.

AHEAD has a website [www.ahead.ie](http://www.ahead.ie) which gives general information about its purpose and activities aimed at students and prospective students with disabilities, their parents, advisors and friends and the academic and administrative staff (in particular, the disability liaison officers of the colleges) who have contact with these students.

#### *Publications: student information resources*

AHEAD has published a number of booklets designed to assist students with disabilities to access third level education and relevant supports. It has published the third edition of *Accessing third level education in Ireland - a handbook for students with disabilities and learning difficulties (1999)*. This handbook outlines the supports available in third level institutions in Ireland, from admission to graduation and examines issues relevant to people with different disabilities. AHEAD has also published *A guide to grants, scholarships and*



*disability benefits for third level students with disabilities in Ireland (1997)*. Another publication is *Third level with a disability - an examination of students' views on third level education and employment opportunities (1998)*.

### *Potential employers*

AHEAD also provides information to potential employers on the recruitment of graduates with disabilities. In conjunction with the IDA, it is currently producing a guide to recruitment and selection of graduates with disabilities.

### *Research*

AHEAD is an independent policy research agency. AHEAD is undertaking a national survey on the nature and extent of disabilities among second level students. This survey has the support and assistance of the Department of Education and Science, the teachers' unions, school governing bodies and parents. The results will form the basis for AHEAD's national policy planning for second and third level education.

### *Action research*

AHEAD has operated a number of action research projects. For example in 1996-1997, AHEAD operated a European Social Fund (ESF) Horizon II project. This project examined experiences and employment opportunities for graduates with disabilities and made relevant policy change recommendations.

In 1998-1999, AHEAD operated a European Social Fund (ESF) Horizon III pilot initiative called *Graduates in Further Training (GIFT)*. This involved 25 graduates nationwide and had connections with FAS, the National Training and Employment Authority. The objective of the initiative was to ensure access to further training for graduates with disabilities. AHEAD used the experience to examine existing policies and develop recommendations to "mainstream" training for people with disabilities.

AHEAD has also operated a transnational partnership project which examined ways to improve access to adult (or second chance) education through the use of distance learning mechanisms. In so doing, AHEAD researched the accessibility of existing open distance learning services for deaf adults in Ireland.

Other areas of research undertaken by AHEAD include ongoing research in the area of students with dyslexia in higher education and admissions policies for students with disabilities. The organisation has an extensive list of publications arising from its research activities, many of which have already been cited here.

### **ADVOCACY SERVICES**

AHEAD has an independent national policy analysis and development role. It seeks to influence institutes of higher education with regard to their policies for access and support of students with disabilities. AHEAD advocates and assists in the establishment of facilities for disabled students, e.g. a central catalogue of material available in alternative formats in academic libraries.

# ALZHEIMER SOCIETY OF IRELAND

Address: Alzheimer House  
43 Northumberland Ave  
Dun Laoghaire  
Co. Dublin

Tel: (01) 2846616  
Fax: (01) 2846030

E-mail: [alzheim@iol.ie](mailto:alzheim@iol.ie)  
Website: [www.alzheimer.ie](http://www.alzheimer.ie)

Chief executive: Maurice O'Connell

## **INTRODUCING THE ALZHEIMER SOCIETY OF IRELAND**

The Alzheimer Society of Ireland was founded in 1982 by a small group of carers of people with dementia. It has grown steadily ever since. In 1991, the society made 2 significant appointments: a national development officer to establish a voluntary management structure nationally and a coordinator of care services to oversee the development of specialised day care centres for people with dementia. Today, the society has an extensive national network of branches and services which provide people with dementia, their families and carers with the necessary support to minimise the impact of Alzheimer's disease on their lives, while always respecting the needs, rights and dignity of the individual.

One of the core functions of the society is the generation of public and political awareness of dementia and its effects on people's lives. The Alzheimer Society of Ireland is currently planning a public awareness campaign about dementia, the first campaign of its kind in Europe. The society wishes to establish consistent and long-term funding arrangements with the relevant statutory bodies as a prerequisite to continued development of service provision for the growing problem of dementia.

## **MEMBERSHIP AND BOARD STRUCTURE**

The Alzheimer Society of Ireland is a membership-based organisation. The society is a company limited by guarantee (since 1984) and its charity number is CHY: 7868. It has a total of 30 branches which are organised into 8 regional committees, corresponding to health board boundaries. Each branch elects 2 delegates to the regional committees which, in turn, elect 2 delegates to sit on the national council, which meets quarterly. The national council also includes 8 directors who are elected on a 3-year rotation.

## **INCOME AND EXPENDITURE**

The Alzheimer Society of Ireland obtains statutory finance and operates a CE scheme, employing more than 200 participants nationwide, with a value of approximately £1.25m per

annum. Fundraising is an important source of income. The national office, in association with the branches, runs a national *Tea day*, in May each year. Money raised by each branch is distributed back to the branch to support its services. Branches also organise events throughout the year to provide funds and to raise local awareness.

The society's service plan for 2000 puts the cost of current service provision at £2,150,000 per annum. The Alzheimer Society of Ireland was allocated £1.1m in the 2000 government budget, to be distributed through the regional health boards. The society obtains an additional £600,000 nett, annually, from national and local fundraising, membership fees etc. The shortfall in statutory income means that the society faces a deficit of almost £500,000 for the present year.

#### **STAFF**

The Alzheimer Society of Ireland has approximately 45 directly employed staff. This includes the chief executive, a management team and 3 administrative staff members. The society has 20 nursing staff around the country who oversee the activities in the day care centres. Other staff include care workers, drivers and cooks.

#### *CE scheme*

The Alzheimer Society of Ireland participates in the FAS CE programme, with approximately 200 workers on 10 different projects. This partnership with FAS is essential for the provision of the society's home support service. The most recent figures show that 40% of CE workers have gone on to find direct employment. CE worker training has 3 phases: induction and pre-placement, placement and in-service training.

#### *Volunteers*

The society has a volunteer commitment through its branch network, and through assistance with services and fundraising.

#### **PREMISES**

The society's national office is based in Dun Laoghaire, Co. Dublin. The day care centres around the country are either purpose-built or leased by the society. All centres have a range of facilities and are fully accessible. Most provide transport to and from the centre by ambulance/minibus. Many of the local support group meetings are held in the day centres at night.

# SERVICES

## INFORMATION SERVICES

### *General information*

The society produces an information pack, containing practical information for the person with dementia and their carer or family. This is distributed free of charge to people who contact the society. The society has a website: [www.alzheimer.ie](http://www.alzheimer.ie) which gives general information on the society and services. The 13 offices around the country also provide information and support to local people on request. The society publishes a quarterly newsletter *Alzheimer News*, with a circulation of approximately 10,000.

### *Drop-in information and support service*

An informal telephone and drop-in information and support service is available at the national office. This is to become a formal helpline by mid-2000 and will be operated by trained volunteers.

### *Public awareness*

The society holds regular meetings at venues around the country. These serve a number of purposes including raising awareness, providing general information and stimulating interest and support for the development of the society and its services in the area. These meetings usually have a medical speaker. The society also provides public speakers for specific groups, e.g. nurses or nursing home staff, when requested.

## MEDICAL/NURSING/THERAPEUTIC SERVICES

Each of the 18 day centres is under the direction of a qualified nurse, who is paid directly by the local branch of the society. Services at the day centres include reality orientation and reminiscence therapy.

## SUPPORT SERVICES

### *Support groups*

The society has more than 37 support groups throughout the country. These are often the first service of a new branch and provide an informal forum for carers to come together to share experiences.

### *Day centres*

The society's 18 day centres provide personal support to people with dementia, their carers and family members. Most of these services start operating on a 2-day week and build up services over time and according to the local resources available, with the ultimate goal of a 5-day week service. Each of the day care centres is managed by a qualified nurse and provides dementia-specific services. Clients may also avail of personal services such as showering, hairdressing etc., facilities which also assist the main carer.

### *Home support and care services*

The home support and care service assigns a trained care worker to a client's home to provide support and respite to the carer for a designated number of hours per week. The society has 10 home support programmes in 17 locations throughout the country. The society also plans to expand these services in conjunction with the health boards.

### *Respite services*

Respite services are available only through the service at Blackrock, Co. Dublin, at present. The service currently operates from Wednesday pm to Friday am to give the carer a break. This is due to be extended to a 4-night service in the immediate future. The society has plans to develop home-based respite services.

### **RECREATION SERVICES**

Each day centre has recreation activities and social events and occasions.

### **ADVOCACY SERVICES**

The Alzheimer Society of Ireland is the national, non-governmental, representative group for people with dementia and their families. The society has ongoing contact with politicians at local and national levels. The society was instrumental in persuading the government to commission the recently published *Action plan for dementia* (National Council for Ageing and Older People). This plan lays out what needs to be done in the immediate future to address the current major gaps in dementia service provision and to meet the predicted rise in the number of people with dementia.

The current foci of the society's lobbying programme include:

- the need for dementia-specific services for people with dementia;
- the serious shortage of State-funded beds for the long-term care of people with dementia;
- the need for more short-term, affordable respite beds;
- the need for a flexible home respite service;
- the need to overhaul the Carers' Allowance and to abolish the means' test;
- the need to address the problem of the cost of long-term care in private institutions *vis a vis* nursing home subvention.

# **APT**

## **AONTACHT PHOBAIL TEORANTA**

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Cormac Street  
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Co. Offaly

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**E-mail:** apt@iol.ie

**Contact:** Liz Scully

### **INTRODUCING APT**

APT is a non-governmental organisation established in 1988 as one outcome of the Midland Health Board's participation in the first EU (then EC) action programme in favour of people with disabilities. APT's role is to develop initiatives to promote the mainstream economic and social integration of all people with disabilities. It seeks to accomplish this aim through mainstream employment projects, housing and public awareness of disability.

APT provides services within the midland counties of Laois, Offaly, Longford and Westmeath. It operates a training and employment service including on-job training programmes and vocational placement services. It manages 7 retail units, based in Midland Health Board hospitals. These shops employ 22 people, of whom 13 are people with disabilities. APT has initiated a community housing programme for people with learning disabilities or a history of mental illness. It cooperates with mainstream and special schools in providing support and advice on vocational assessment.

Its activities include action research, pilot studies and development of replicable standards of good practice in training and employment for the wider disability sector. It has formed ongoing partnerships with similar groups in other European states as part of transnational EU initiatives and was selected as 1 of 8 Irish organisations to participate in the economic integration section of the Helios II programme.

APT recognises the significant changes occurring with the disability sector and the shift in the responsibilities of the statutory bodies, all of which could have an impact on the future services of APT. In particular, APT notes the change in responsibility for level 2 vocational training from the Department of Health and Children to the Department of Enterprise. It also notes the dissolution of the National Rehabilitation Board. In view of these sectoral developments, APT has initiated a company review to inform and influence its future role.

## **MEMBERSHIP AND BOARD STRUCTURE**

APT is not a membership-based organisation. It is a company limited by guarantee. Its charity number is CHY: 8206. The board of directors comprises 9 members, with rotation every second year. The board meets 8 times a year.

## **INCOME AND EXPENDITURE**

APT is funded by means of profits from the shops, rents from its housing programme and professional fees for the provision of its services. Its main source of contracts is the Midland Health Board and it also provides services for the Mid Western Health Board. APT's turnover is just less than £300,000 per annum. APT does not seek charitable funding.

## **STAFF**

APT employs 30 staff members, 8 of whom have management and administrative roles. APT does not participate in any CE scheme and has no volunteers. APT has formal safety, complaints and reporting mechanisms. It undertook an internal organisational evaluation in 1999. Its involvement in EU programmes and projects requires that these projects are evaluated through interim and/or final reports. APT actively encourages staff to expand their skills and knowledge.

APT works closely with the Employer Task Force, an advisory body of senior employers from the public and private sectors. Staff members hold honorary positions on national umbrella and other representative bodies including Disability Federation of Ireland (DFI) and the National Accreditation Committee (NAC). It has ongoing links with CNEASTA (the Irish council for training, development and employment for persons with disabilities) and the Irish Union of Supported Employment. The APT general manager is on the disability advisory group of the Westmeath partnership. This committee seeks to represent the views of people with disabilities and to enable the establishment of suitable projects.

## **PREMISES**

APT has offices with disabled access and facilities.

# **SERVICES**

## **INFORMATION SERVICES**

APT operates a mobile information/help desk as part of its training and employment service. Financial support for this service is obtained through the People in Need trust and the Midland Health Board.

## *Publications*

APT produces an annual report. It also publishes brochures about its services and a series of leaflets describing its activities.

## *Research*

APT undertakes action research projects as part of its brief. This means that it undertakes projects which aim to examine underlying issues in relation to training and employment for people with disabilities. Its action research *RAPPORT* project, which ended in 1992, identified barriers to the employment of people with disabilities from an employer's perspective. The European Social Fund (ESF) subsequently funded an employer-based training project, based on the findings of the initial research. This initiative has already proven successful at national level.

Another action research project was called *Options*. This was jointly funded by the EU Horizon programme and the Midland Health Board (MHB). The project included personal development, job preparation, on-job training and ongoing support for people living with mental health problems. The results of this project have led to the development of other initiatives in the area.

APT also cooperated with 3 other agencies, St. Michaels' House, St. John of God and KARE in a project called *Connect*. This was a pilot project aimed at finding suitable employment for adults with learning disabilities who were long-term unemployed. The project involved working with parents, employers, support staff and trainees. This initiative showed that, given the appropriate approaches and funding, many people with learning disabilities can enter or return to the workforce.

APT has also been active in developing assessment criteria which aim to provide a structure within which people with disabilities are matched with appropriate employment opportunities. This project, called *Resolve*, was assisted with funding from the EU innovatory funding support programme. Through this project, APT developed the *Resolve* assessment system which facilitates the gathering of crucial information, in simple terms and in a structured format. This allows the skills of potential employees to be matched with employment opportunities. It also permits identification of gaps between an individual's abilities and the requirements for a particular job and highlights the support or training necessary to enable the person to take up the employment.

APT has also participated in transnational pilot projects in areas such as transitional support to work finding and retaining employment for people with disabilities. As part of this project, APT, in cooperation with a Netherlands organisation, drew up standards of good practice. It has also participated in two European exchanges of information projects within the Helios programmes.

## **EDUCATION SERVICES**

Since 1998, APT has cooperated with mainstream and special schools in the midland region to provide vocational assessment support and advice to individuals with disabilities, their parents and teachers. APT has plans to provide computer training for children with a disability.



## **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

In 1999, APT assisted 71 people with disabilities, 45 of whom were self referrals.

### *Assessment service*

APT provides an assessment service for all people referred for training or employment placement. APT accepts referrals from the National Rehabilitation Board (NRB), other statutory and voluntary organisations and by self-referral. In the course of 1998, APT assisted 80 people with disabilities, of whom 30% had physical disabilities and 21% had mental health difficulties and 49% had learning disabilities.

Many of APT's action research projects have substantial core training, placement or employment facets. In 1998, APT completed the formal process in preparation for national accreditation of its employer-based training services. In 1999, APT became the first company to attain the National Accreditation (Approved Centre) Award for employer-based training services for people with disabilities.

### *Work experience to employment service*

APT's action research RAPPORT I project, initiated in 1990, involved 18 companies in the midland region. These companies initially provided work experience and later employment to a group of people with disabilities. Rapport II, established in 1992, provides a link between training and employment through job training programmes in cooperation with employers, funded through the European Social Fund (ESF). This service includes career advice, job matching, identification of a suitable training company, an individual training programme for each trainee to include support and an employment placement service on completion of training. Trainees are paid a training allowance. Some individuals qualify for travel allowances. All trainees maintain social welfare benefits during training. To date, 70% of the trainees involved in the APT employer-based training programmes have found jobs, typically with the participating companies.

### *Employment placement service*

APT offers an employment service which helps people with disabilities to decide on the type of work they wish to do, assists in finding suitable employment in the midland region, prepares candidates for interviews, arranges work experience if necessary, provides support in the initial stages of employment and identifies relevant employment or social welfare schemes and employment incentives.

### *Job placement service*

APT has operated an Employer Task Force initiative which aimed to find jobs for people with disabilities who had been unsuccessful to date in gaining employment but who had vocational skills of some kind. This project was part-funded by the MHB. APT acted as a job placement agency tapping its extensive network of employers, utilising its job matching systems and providing necessary initial employment support.

### *Employment initiatives*

APT manages 7 Cheers! shops in the MHB hospitals in Tullamore, Portlaoise, Mullingar and Mountmellick. Most of the staff of these shops are people with disabilities. The shops also give retail sales training to trainees with disabilities. These businesses are run on a commercial basis

and shop staff are paid wage rates comparable to other similar commercial operations. Some of the shops also run coffee docks and a paper round service is available on the wards of the general hospitals involved in the scheme. The net profit from this activity is used to fund other projects undertaken by APT.

*Supported employment service*

APT has recently established a working partnership with a number of local service providers in order to develop a supported employment service in the area. Some of the staff from these agencies have obtained certified coach training for this purpose. This initiative was funded by the Tullamore Wider Options Group Ltd.

**HOUSING SERVICES**

APT has a housing programme which caters for more than 100 people at 12 locations in the midland and mid-west regions. All of the tenants of the homes are people with learning disabilities who, prior to completing a rehabilitation programme, were accommodated in long-term residential facilities. These people now live in their communities with minimal professional support. This opens up opportunities of training and employment, and social, recreational and sporting activities. The properties are funded through the Department of the Environment voluntary housing scheme, administered by the local authorities. Tenants pay rent and help with day-to-day maintenance and upkeep of their homes.

Location of homes	
County	No. of houses
Longford	4
Westmeath	3
Laois	2
Limerick	2
Clare	2
Offaly	1
<b>Total</b>	<b>14</b>

# THE ARTHRITIS FOUNDATION OF IRELAND

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Tel: (01) 6618188

Fax: (01) 6618261

E-mail: [info@arthritis-foundation.com](mailto:info@arthritis-foundation.com)

Website: [www.arthritis-foundation.com](http://www.arthritis-foundation.com)

Administrator: Sheila Gorman

Cork development officer:

Una Harte  
17 Dunville Crescent  
Waterfall Road  
Bishopstown  
Cork

Tel: (021) 345263

## INTRODUCING THE ARTHRITIS FOUNDATION OF IRELAND

The foundation was set up in 1981 and promotes research and education into all forms of arthritis. Its goal is to help people with the range of arthritic conditions to have an improved quality of life. The major concerns of the Arthritis Foundation of Ireland include the ongoing need to raise funds for research. The foundation is critical of existing taxation impositions on charities, specifically Value Added Tax (VAT).

## MEMBERSHIP AND BOARD STRUCTURE

The foundation deals with more than 100,000 queries from members and from the public every year. It has 5,000 individuals on its mailing list. The foundation has a network of branches throughout the country (Cork, Dublin, Donegal, Kildare, Limerick, Mayo). *Friends of the Foundation* was established in 1998 as a special membership group with a fee of £20 per annum. It informs people about developments in arthritis research and treatment and gives news of forthcoming foundation events. To date 1,000 people have subscribed.

## ARTHRITIS

Arthritis is the medical word for joint inflammation. There are more than 100 different types of arthritis. Most are chronic conditions which cause pain, swelling and loss of movement of the joints. Arthritis is the leading cause of disability in Ireland today: 1 in 7 people has some form of arthritis.

Osteoarthritis is by far the most common form of arthritis in Irish people, and is much more common in women than men. It is caused by a breakdown of cartilage in the surface of joints. Most people with osteoarthritis maintain a normal life.

Rheumatoid arthritis is an auto-immune disease in which the body's defence mechanisms attack the joints. About 1 in every 100 people has this condition. Women are much more likely to have the condition than are men. Juvenile arthritis is usually mild, but sometimes requires long-term treatment.

We still do not know what causes most of the arthritic conditions. At present, no cures exist for any of the main arthritic conditions. There are many ways of treating and slowing their progress. Drug therapy can alleviate symptoms and slow the progression. Moderate exercise, good diet, adequate rest and avoidance of stress are all beneficial.

The Arthritis Foundation of Ireland is a company limited by guarantee. Its charity number is CHY: 6297. The board of management comprises 17 members, elected at the Annual general meeting (AGM). The rotation of board membership is every 2 years.

#### **INCOME AND EXPENDITURE**

In 1998, the Arthritis Foundation of Ireland had a total income of £225,000. The foundation benefits from bequests: in 1998 it received £54,000 in this manner. The Arthritis Foundation of Ireland actively seeks corporate sponsorship. In 1998-1999, Searle Ireland contributed £10,000 to the Dublin information day, Smith Kline Beecham gave £2,500 for publications, Smith & Nephew and the Elan Corporation both gave £2,000 for leaflet production. Cork voluntary organisations gave funds, namely the Cork Federation of the ICA (£6,000) and the Lions Club (£1,500). Among the annual events held to raise funds for the foundation are a rugby dinner, an award dinner, occasional university rag week collections, musical events, sale of Irish charity cards, church gate collections, film premieres, fashion shows, marathon participation and branch fundraising.

The State provided £6,600 through the Department of Health and Children lottery allocation to upgrade the foundation's photocopier. The Eastern Health Board provided £1,000 to the Kildare branch for computers and £800 for a self help course and £1,000 to the Dublin Information Day. The Health Promotion Unit gave £2,800 in sponsorship of the Juvenile Arthritis book. The Arthritis Foundation of Ireland has no involvement with the FAS Community Employment (CE) programme.

#### *Expenditure*

In 1998, the foundation spent £185,000. Information/education activities cost £82,000, community activities, including information days, cost almost £40,000, administration costs were £34,000, premises leasing and overheads accounted for almost £14,000. Any surplus income was allocated to arthritis research.

#### **STAFF**

The Arthritis Foundation of Ireland has 3 full-time and 1 part-time staff. The staff includes an administrator, an information officer, an education officer and a fundraiser. All staff have appropriate qualifications.

#### *Training, monitoring and evaluation procedures*

There are no formal induction or other in-house training programmes. Safety and monitoring procedures for clients are inapplicable. There is an internal reporting mechanism. The foundation can call on the support of a number of volunteers for specific projects including routine administrative tasks and fundraising.

#### **PREMISES**

The Arthritis Foundation of Ireland is located in a two-storey building with complete disabled access, open plan offices and a boardroom. The offices are computerised.

## SERVICES

### INFORMATION SERVICES

The Arthritis Foundation of Ireland's primary role is as an information service. The foundation has a web-site [www.arthritis-foundation.com](http://www.arthritis-foundation.com)

#### *Lectures/seminars/information days*

The foundation hosts information lectures by healthcare professionals throughout the country. In 1998, lectures were held in Dublin, Cork, Clare, Galway, Tipperary, Donegal, Kildare, Limerick, Mayo and Roscommon. It also holds an arthritis information day annually in Dublin and Cork. This day comprises information, exercise demonstrations, videos and lectures. In 1998, 1,200 visitors attended the Dublin event and more than 600 visitors came to the Cork day. The foundation also had an exhibition stand at the Irish Society of Rheumatology conference and the Irish Nurses' Guild conference. The foundation holds an arthritis family day annually for families with children with arthritis. In 1998, this event was held in Dublin Zoo.

#### *Media publicity*

The Arthritis Foundation of Ireland actively seeks media publicity for its services and events, particularly focussed on its annual information days. It has undertaken poster campaigns sent to general practitioners (GPs) surgeries, libraries and branches.

#### *Publications*

It publishes a range of leaflets, brochures and booklets about aspects of the main arthritic conditions. Each year, the foundation seeks to introduce new topics. In 1998, approximately 70,000 leaflets and newsletters were distributed by the foundation at information days and lectures, through the branches and to health care professionals, health boards and libraries. Some of these leaflets are sponsored by drug or health product companies. Others have been funded by the Health Promotion Unit.

The publications include general descriptions of arthritis (osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, juvenile arthritis and gout). Specific leaflets deal with concerns in relation to arthritis and pregnancy, hip replacement, medication and employment. The foundation publishes information directed at children, teenagers and parents. It publishes a quarterly magazine, *Arthritis news*, which is sent to more than 2,000 individuals, and a twice yearly newsletter for parents (print run: 1,000). An annual review is also produced.

The foundation publishes a set of *Personal Arthritis Coping Tools*, (PACT) which costs £2 and contains 8 leaflets on issues such as stress, joint protection, pain, unproven remedies, exercise and food. It also publishes a *Move it or lose it* workbook (£4.70 a copy) which is a guided programme of physical exercises.

### *Research*

The Arthritis Foundation of Ireland actively funds research into the conditions. At present, it is assisting the financing of an investigation of pro-inflammatory cytokine interleukin 1, at Dublin University, Trinity College, through its Arthritis Foundation Scholarship. In 1999, the foundation established a research fund of £100,000 and is presently seeking matching funds from the Health Research Board. By 2001, the Arthritis Foundation of Ireland will have spent £700,000 on research projects.

### **SUPPORT SERVICES**

#### *Branch supports*

Branch members keep in contact and form informal support networks. The Arthritis Foundation of Ireland operates a scheme called *Telephone buddies*. This enables parents whose children have arthritis to maintain contact and to share problems and concerns.

#### *National arthritis family day*

This is an annual event and enables families with children with arthritis to meet and enjoy a social event and to make friends and gain support.

#### *Equipment purchase or loans*

The Arthritis Foundation of Ireland produces a large mail order catalogue of items to assist people with arthritis in activities of daily living. The items for sale include walking sticks, walking frames, wheelchairs, ramps, personal hygiene requisites, bathroom accessories, beds and chairs, pressure relief pillows, footwear, joint protection wear and special cutlery.

# **ASPIRE**

## **ASPERGER SYNDROME ASSOCIATION OF IRELAND**

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**Fax:** (01) 7043238

**Contact:** Des McKernan

### **INTRODUCING ASPIRE**

ASPIRE was founded in 1995. Over the last 5 years, it has developed information, support, education and training services for parents of and children with Asperger syndrome. The association's main successes to date include the establishment of a special primary school class and a European Union (EU) Horizon-funded supported employment project for young people with Asperger syndrome.

The association has developed a 3-year plan for 1999-2002. This builds on the association's achievements to date and seeks to expand in specific areas. The main task confronting the association at present is to obtain the funding element for this plan. It has made an application to the Eastern Health Board (EHB) in this regard. Ongoing concerns for ASPIRE include obtaining Department of Education and Science funding for post-primary support of young people with Asperger syndrome. The association would also benefit from permanent office premises.

### **MEMBERSHIP AND BOARD STRUCTURE**

The membership of ASPIRE is family-based and consists of about 300 families. There is 1 branch outside Dublin, in Limerick, covering the Mid Western Health Board region. ASPIRE is a company limited by guarantee. Its charity number is CHY: 11438. The board consists of 7 members, with rotation every two years and approximately 9 meetings per annum.

### **INCOME AND EXPENDITURE**

ASPIRE has received about £240,000 in total from the EU Horizon programme (European Social Fund) in the past 2 years. It has also received £4,000 from the Eastern Health Board (EHB) respite fund. ASPIRE has obtained charitable trust donations from People in Need -

### **ASPERGER SYNDROME**

Asperger syndrome is the name given to a puzzling condition in which a child of average or above-average intelligence has serious difficulties in making interpersonal social relationships. Many researchers have considered that children with this presentation have autism in the presence of significant intellectual ability. Sometimes, the person with Asperger syndrome may show extremely well developed skills in a particular area of intellectual functioning.

Children with Asperger syndrome require significant social and other psychological supports. They can often attend mainstream schooling, particularly if they have ongoing support. The majority of adults with Asperger syndrome will require assistance to lead fulfilling lives and to use their abilities to their maximum capacity.

£5,000 for the purchase of computers etc. The association obtains small sums from Christmas raffles (October -December each year), garden parties and from sponsorship in the women's min-marathon. ASPIRE does not participate in the FAS CE programme.

#### **STAFF**

ASPIRE has 3 paid staff (1 is administrative), with a total staff wage cost of £67,000 per annum. Two staff members are following a diploma course in supported employment. ASPIRE sees value in developing accredited training programmes for staff. ASPIRE also has 6 volunteers. The volunteer programme costs the association about £3,000 - £4,000 per annum. Volunteers occasionally attend training courses run by the Carmichael Centre in Dublin. The association has no formal volunteer recruitment or retention strategies.

#### **PREMISES**

The supported employment project has an office in Patrick's Street, Dun Laoghaire, Co. Dublin and is computerised. The office has no disabled access. ASPIRE hopes to obtain office space in the Carmichael Centre, north Brunswick Street, Dublin 7, in 2000. Volunteers operate the helpline from their own homes.

## **SERVICES**

#### **INFORMATION SERVICES**

ASPIRE gives information to any parent with a child with Asperger syndrome. The association also provides information books and videos. It holds parents' days, workshops and seminars to inform members. The association is currently developing a self-promotion, public awareness campaign. It attempts to obtain publicity for its fundraising events through the spoken and written media.

#### *Publications*

ASPIRE publishes an annual report for members, a newsletter twice or three times a year and occasionally publishes the proceedings of conferences.

#### **EDUCATION SERVICES**

ASPIRE assisted in the establishment of a special class at St. Peter's National School, Walkinstown, Dublin 12, funded and operated by the Department of Education and Science. The association is working with the Southside Partnership to provide a support structure in 2 post-primary community schools in Dublin, Cabinteely and St. Tiernan's, Dundrum.

ASPIRE organised a course of 7 lectures at the Froebel College, Blackrock, Co. Dublin, held in September - November 1999.



## **SUPPORT SERVICES**

### *Helpline*

ASPIRE operates a helpline which puts parents in touch with others in their local area. Volunteers occasionally visit families, newly diagnosed or with problems. The association's 3-year development plan sets out areas for expansion of services.

### *Respite services*

ASPIRE provides respite grants through funding from the EHB.

## **VOCATIONAL/EMPLOYMENT SERVICES**

ASPIRE operates a EU Horizon-funded supported employment service which includes a work placement. ASPIRE is keen to ensure the continuation of this service after the Horizon funding ceases in March 2000.

A training course has recently started for people with Asperger syndrome aged 16 years or older. It is operated by EVE Holdings on behalf of the association. Called *Transition to employment*, it includes training in the areas of life skills and independent living. It is currently operating in a temporary location in Ranelagh, Dublin 6, but permanent premises are sought. A similar course will be organised for the Mid Western Health Board region through the Limerick branch of ASPIRE.

## **HOUSING SERVICES**

ASPIRE wishes to provide supervised accommodation. The association is recognised by the Department of the Environment for capital assistance purposes. As an approved body, the EHB has promised it support for this service. In 1998, the association made 2 unsuccessful attempts to purchase suitable accommodation and continues to seek suitable premises.

## **ADVOCACY SERVICES**

ASPIRE is the national representative body for families with a child with Asperger syndrome. As such, the association campaigns for improved State services for its membership. ASPIRE lobbied for the establishment of a primary school class. It has also sought the establishment of a central diagnostic service in the Dublin region. It has made representations to the Department of Education and Science in relation to inclusion of information on Asperger syndrome in teacher training, and for special provisions for young people with the condition during formal examinations.

The association also provides advocacy assistance to individuals and families. It makes representations to government departments and health boards on behalf of members. It also occasionally intervenes in school-related problems.

## ASTHMA SOCIETY OF IRELAND

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Nurses' tel: (01) 8788122 (Thursday  
9.30 am - 5.30 pm)  
Asthma line: 1850 44 54 64 (24-hour  
prerecorded information  
about asthma)

Fax: (01) 8788128

E-mail: [asthma@indigo.ie](mailto:asthma@indigo.ie)

Contact: Genie Hennessy

### INTRODUCING THE ASTHMA SOCIETY OF IRELAND

The Asthma Society of Ireland was founded in 1973. The purpose of the society is to provide information, support and reassurance to people with asthma and their families, to act as their advocate and representative at national and regional policy making and implementation levels and to promote awareness and understanding of the condition amongst the general public. The society aims to ensure that people with asthma can realise their full potential. It highlights and seeks to eliminate health service, social or financial disadvantages incurred by people with asthma.

The society was instrumental in the campaign that led to the Department of Health and Children introducing the Drug Cost Subsidisation Scheme in 1990. Its annual asthma information day is always well attended. Ongoing concerns include ensuring funding.

### MEMBERSHIP AND BOARD STRUCTURE

Membership is open to all and costs £5. The Asthma Society of Ireland has 11,000+ names on its data base, 3,000 of whom renewed their membership in the last 2 years. Information services are available to nonmembers. At one time, the society had 25 branches nationally, this has decreased to 9 in 1999. The society is launching a branch development drive over the next

### ASTHMA

Asthma is a condition which affects breathing. During an asthma attack, the air passages to the lungs contract and this makes breathing difficult. It can also lead to panic which may make the attack worse. When a person has an asthma attack, they should remain calm, focus on breathing out fully, sit upright and not lie down and use their inhaler, if available.

Asthma is a common problem affecting about 1 in every 20 adults in Ireland and about 1 in every 5 children. The prevalence of the condition is increasing annually. The precise cause of asthma is not known. Attacks are triggered by allergic and non-allergic factors. The most common allergy trigger is to the faeces of the common house dust mite. Asthma has also been linked to allergies to dairy products and to some food additives. Non-allergic factors include genetic inheritance of a predisposition to the development of asthma.

The treatment of asthma has improved in the last number of years. Many people with asthma use inhalers which provide a mist of medicine directly into the lungs which acts to prevent and relieve the asthmatic attacks. It is important to use the inhaler correctly as otherwise the benefit of the medicine may be lost.

People with asthma should seek to have an active lifestyle with aerobic exercise to maintain or improve lung capacity.

three years. The Asthma Society of Ireland is a company limited by guarantee. Its charity number is CHY: 6100. The board of management comprises 8 members at present and includes (lay) people from the membership, doctors and respiratory experts from the medical board. Directors must retire every three years, but may stand for reelection. Meetings occurred as and when required. There are no upper or lower age limits for board membership.

#### **INCOME AND EXPENDITURE**

The Asthma Society of Ireland had an income of approximately £203,000 in 1998. Income came from the State, with a Department of Finance grant for £100,000 and an Eastern Health Board grant of £7,000. No other health board contributed funds to the society. It also received a grant of £4,000 from the Health Promotion Unit in connection with publications. The society's participation with the FAS CE programme is separately valued at approximately £70,000. Fundraising in 1998 consisted of draws, donations from pharmaceutical firms, cycle & golf classics which produced £ 55,000. Lottery scratch cards' income came to £55,000. People in Need contributed £5,000 and sales of materials brought in £2,300.

#### *Expenditure*

The Asthma Society of Ireland spent £160,000 in 1998, including £70,000 on directly paid staff. Other costs include the part-time asthma specialist nurses, asthma information days and the mobile asthma unit.

#### **STAFF**

The Asthma Society of Ireland employs 2 directly paid staff. The society employs 3 asthma specialist nurses for variable periods part-time. It also has 8 CE workers. All staff are administrative, while 2 also are involved in newsletter production, lobbying etc. In all, 2 staff members have relevant qualifications. Approximately 10 branch members volunteer to help out at the asthma information days. The volunteer programme is not costed.

#### *CE scheme*

The CE scheme is vital to the functioning of the society. The volume of calls, mail and faxes, received on a daily basis, demands significant staff resources, but the society could not fund the required numbers of full-time staff. The scheme has a successful placement rate for CE workers, so there is constant turnover of staff.

#### *Training, monitoring and evaluation procedures*

CE workers are given an induction course and are trained on the procedures/systems in place to ensure a follow-through of all queries, and also on all the computer applications and the various machines – fax, photocopier, franking machine, laminating machine etc. The society does not operate any staff accredited or in-house training programmes and sees no immediate value in developing accredited training programmes for new CE participants as they receive accredited training from outside agencies. The society does not have volunteer recruitment and retention strategies.

The Asthma Society of Ireland has written fire procedures. It does not have a written complaints procedure but has internal reporting mechanisms. Volunteer safety procedures and monitoring of volunteer activity are not necessary given their limited involvement in the society. The society is currently conducting an independent evaluation of the staffing structure and an internal review of its lottery funding reliance. It has not conducted any other external or internal reviews.

#### **PREMISES**

The Asthma Society of Ireland is located in rented offices without disabled access. Staff have access to 4 computers. People can drop in for information and to buy peak flow meters at any time during office hours. They can drop in on Thursdays to see the asthma nurses. The premises include a large board room. The society may have to move premises due to increased costs.

## **SERVICES**

#### **INFORMATION SERVICES**

The Asthma Society of Ireland provides an extensive information service to the general public and to its members and contacts. It responds to queries by 'phone, fax and e-mail. The society operates a call save number 1850 44 54 64.

#### *Public awareness*

The society holds an asthma information day in October of every year. The society holds a list of asthma nurses and doctors who will talk at local meetings throughout the country on request.

#### *Media campaigns*

Press releases are sent out prior to all society events (3 per year).

#### *Publications*

It produces fact sheets, leaflets and a booklet about asthma. One of the leaflets is called the *Five minute rule* and explains what to do in case of an emergency – this goes out in an information pack sent to everyone who 'phones, faxes, writes or e-mails for information. The society has a video on teenage asthma and a leaflet on asthma in school for teachers. It produces a regular newsletter 3 times a year but does not have an annual report.

#### *Plans for information services*

In July 1999, the society adopted a development plan to better meet the information needs of its members. A review of publications focussed on the need to target written information to members. The society has plans to develop a web page including one section devoted to children and young people. A video on asthma is in the pipeline. The society intends extending its asthma information day to at least one region, in addition to the event in Dublin.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

The society employs asthma specialist nurses who attend at the office on Thursdays 9.30 am to 5.30 pm to respond to all queries.

The society has a mobile asthma unit. This caravan is fully-equipped with asthma related software and is brought to venues, as requested, throughout the country. It is staffed by specialist asthma nurses who give information on equipment and medication used in treating asthma.

#### *Plans for nursing services*

The "asthma live line" (specialist asthma nurses) will be extended to two days from January 2000 - Tuesdays and Thursdays.

### **SUPPORT SERVICES**

The society has a network of informal support through its branch structure. It is in the process of increasing the number of branches.

#### *Helpline*

Thursdays – asthma live line on (01) 8788122, see nursing service above.

#### *Equipment purchase or loan*

The society sells peak flow meters which assist people with asthma to measure how well their treatment is working.

### **RECREATION SERVICES**

#### *Sporting activities*

Some branches hold local swimming galas.

### **ADVOCACY SERVICES**

The Asthma Society of Ireland seeks to represent the views and needs of people with asthma nationally. The society continues to approach government on issues relating to all affected by asthma. It looks to the Department of Health and Children to provide assistance to families with one or more members with asthma in purchasing equipment needed to take medication and to defray the cost of frequent visits to their general practitioner (GP). The society lobbies the Department of Environment to ban bituminous coal.

# AWARE

## HELPING TO DEFEAT DEPRESSION

Address: 72 lower Leeson Street  
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Helpline: (01) 6766166  
(10.00 am -10.00 pm every day)

E-mail: aware@iol.ie

General manager: Geraldine Clare

### INTRODUCING AWARE

Aware was founded in 1985 by a group of people including individuals being treated for depression, their relatives and mental health professionals. It is an all-Ireland organisation. It aims to assist people whose lives are directly affected by depression. Aware seeks to inform public opinion and to galvanise positive responses to people with depression. The organisation also promotes research into the causes and effective treatments of depression and elation.

### MEMBERSHIP AND BOARD STRUCTURE

People with depression, their families and friends can join Aware. Services are provided to nonmembers. Branches of Aware operate as weekly/fortnightly support groups usually for people with depression, although some also have support services for family members. (All branches which provide both patient and relative support groups are marked \*). The branches are Athlone, Ballaghaderreen, Bray\*, Carlow\*, Carrickmacross\*, Castlebar\*, Castleblayney\*, Cavan, Clonmel, Cork\*, Drogheda\*, Dublin (Cabinteely, Dublin central\*, Dublin central, northside, southside, Tallaght), Dundalk\*, Dungloe, Ennis\*, Galway\*, Gorey, Kells, \* Kilkenny\*, Killarney\*, Leitrim\*, Limerick\*, Longford, Monaghan\*, Nenagh, New Ross, Portlaoise, Roscommon\*, Sligo\*, Tralee\*, Tramore\*, Tuam, Tullamore\*, Waterford\* and Wexford\*. A youth group meets in Dublin. In addition, Aware has patient and

### DEPRESSION

Depression is a widespread problem which can take many forms, from short-lived feelings of sadness that most of us experience, from time to time, in response to the disappointments of daily life, to severe disorders which require medical and/or psychiatric treatment.

Medical specialists class depression under distinct headings: reactive and endogenous. Reactive depression may occur after an unhappy or distressing event in a person's life, such as bereavement marriage breakup or loss of employment. The symptoms include feeling very low for an extended period and anxiety, anger and irritability. Some people are more vulnerable to reactive depression than are others and quite minor upsets in their lives can lead to serious symptoms.

Endogenous depression is caused by a chemical or biological imbalance in the brain which may be provoked by traumatic events. The symptoms include extreme fatigue, feelings of sadness, despair, suicidal thoughts and social withdrawal. Manic depression has identical symptoms to endogenous depression but is accompanied by spells of elation and euphoria, known as mania.

In recent years we have seen extensive developments in pharmaceutical and psychotherapeutic treatments of depression. However, there are still many individuals who do not respond to any current treatments. All people with depression are assisted by understanding and support. At present, public awareness of depression is limited and sometimes unhelpful.

relative support groups in Northern Ireland in Ballinahinch, Belfast, Dunmurry, Enniskillen, Omagh, Strabane and Newry.

Aware became a company limited by guarantee in 1996. Its registered charity number is CHY: 6748. The board of directors consists of 14 members and meets 12 times per annum. Board membership rotates each year, except for officers.

#### **INCOME AND EXPENDITURE**

For the year 1999, Aware had a total income of £693,848. This comprised £488,274 from fundraising, sporting and promotional entertainment events, £121,046 from subscriptions, sponsorships and donations, £19,840 from publications and promotional items and £54,688 from other income sources.

The total obtained by Aware from health board and government departmental sources was £31,200. For the group's accountancy purposes these are categorised as unrestricted (may be applied to any expenditure) and restricted (earmarked for a particular project) grants. The unrestricted grants came to £10,000 (Eastern Health Board £6,000, North Eastern Health Board £4,000) and restricted health board and central government grants accounted for £21,200 (Eastern Health Board £3,000, Mid Western Health Board £3,000, North Eastern Health Board £2,700, South Eastern Health Board £1,500, Southern Health Board £2,000, Department of Social Community and Family Affairs £9,000).

#### *Expenditure*

Aware's expenditure included £229,917 on fundraising expenses, or approximately half of all income derived from this source. Support costs amounted to £192,473, including £67,043 on staff costs, £26,405 on loan interest, and £12,784 on consultants' fees. It spent £107,326 on publications, awareness education and research and £31,630 on administration costs.

#### **STAFF**

Aware has a total of 8 staff members: 3 administrative, 1 fundraiser, 1 education officer, 2 regional coordinators and 1 general manager. Aware also has 6 CE workers, 2 of whom work in administration and 4 who work in the charity shop. Aware has 40 volunteers who work on the helpline, while the organisation has a further volunteer base of more than 2,000 people who help with fundraising and other projects.

#### *Safety, monitoring and evaluation procedures*

Aware has volunteer recruitment, retention and training strategies. The organisation's health and safety strategy is currently under review. Aware conducts internal and external organisational reviews regularly; for example, it surveys its support groups annually.

#### **PREMISES**

Aware operates from offices in Dublin 2. These consist of a terraced building with 5 floor levels. The building does not have disabled access. The nationwide support groups meet in local facilities, often a local school or day centre.

## SERVICES

### INFORMATION SERVICES

Aware provides an information service on depression and elation. It provides leaflets on these topics and about its services throughout the country. It has a library of titles about depression.

#### *Public lectures*

Aware has an ongoing programme of public lectures, which take place in Dublin and at venues throughout the country. It also gives talks to secondary school classes. It runs a schools' campaign which involves an essay competition with cash prizes.

#### *Fundraising publicity*

Aware is almost entirely reliant on fundraising. It produces publicity material to aid in obtaining funds from a wide range of charitable, sponsorship and business sources.

#### *Publications*

Aware publishes a quarterly magazine, *Aware*, which is sent to members and associates. It also publishes *Beat the blues* bulletin, a school project in health education and social awareness. Aware publishes its financial statement annually and it hopes to provide an annual report for the year 2000.

#### *Research*

Research into the causes of depression is one of the core objectives of Aware. To this end, the organisation is involved in research on an ongoing basis.

### SUPPORT SERVICES

One of the core features of Aware's work is the nationwide support group network. These groups meet on a weekly or fortnightly basis and provide an opportunity for people with depression to meet others in a similar situation. In many areas, specific relatives' groups coexist and give family members an opportunity to gain support and encouragement from their peers.

### ADVOCACY SERVICES

Aware seeks to promote the best management and maximal social integration of people with depression. It campaigns for improved psychological and psychiatric services, particularly the development of a national counselling service. Staff will act as advocates for clients in seeking entitlements, in obtaining information and services.



# BRAINWAVE

## THE IRISH EPILEPSY ASSOCIATION

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Director: Mike Glynn

### INTRODUCING BRAINWAVE, THE IRISH EPILEPSY ASSOCIATION

Brainwave was founded in 1967. It is a member's organisation for people with epilepsy. It provides information, advice, counselling, aids, training and advocacy services. In the past 10 years, it has seen significant growth and now has offices in each of the health board regions, except the Midland Health Board (where it has an active members' group), with locally paid service staff. Brainwave has also developed a number of vocational pre-employment training courses with funding from the European Social Fund (ESF). In 1997, the world epilepsy congress was held in the Royal Dublin Society (RDS) and was attended by 5,000 delegates.

Brainwave points to the ongoing stigma against epilepsy in Ireland as a significant social barrier for members. It is also critical of the lack of specialist services, including neurology, epilepsy specialist centres and epilepsy specialist nurses for people with epilepsy. At present, there is no epilepsy centre in this country, whereas most European countries have had centres for more than 100 years.

### EPILEPSY

Epilepsy is the term used for the continuing tendency to have seizures. Anyone can have a seizure at any time, but it is much more likely to occur in childhood and early adolescence or in later life. About 1 in 20 people will have a single epileptic seizure at some time in their lives. At least 1 in 200 people has a tendency to have recurrent seizures. This means that 25,000 Irish people have recurrent seizures.

In about 60% of all instances, no obvious cause can be found for epilepsy. Some well-known causes of epilepsy include head injuries, strokes and brain infections and injuries before or at birth.

Some people "grow out" of epilepsy, while others continue to have the condition for a long time. Most people, between 75%-80%, with ongoing epilepsy find that modern drug treatments control their seizures and they can live full lives. Some people find that epilepsy interferes with their lives and about 10% of people with epilepsy may have their seizures reduced or eliminated by surgery.

Tragically, more Irish people die each year from epilepsy than from sudden infant death syndrome. Some of these epilepsy deaths could be avoided if people, especially young men, who are most at risk from sudden unexpected death from epilepsy (SUDEP), took some sensible precautions, including the use of a safety pillow and ensuring nighttime access to bedrooms. They should also observe a lifestyle favourable to their condition; getting regular sleep and meals, always taking their anti-epileptic medications at the correct times and avoiding the abuse of alcohol and street drugs.

It is almost certain that many epilepsy deaths could be avoided if sufficient research were carried out. Funds available for epilepsy research generally are minute or nonexistent when compared to the sums spent on conditions such as AIDS, heart disease and cancer.

## **MEMBERSHIP AND BOARD STRUCTURE**

Brainwave is in regular contact with about 7,000 individuals in Ireland, of whom many are, or were, paid members of the association. Initial services are currently provided to any person with epilepsy, regardless of membership of the association. This policy is under review. Brainwave has branches in Cork, Dublin, Dundalk, Galway, Letterkenny, Limerick, Sligo and Waterford.

Brainwave is a company limited by guarantee. Its charity number is CHY: 6170. The board comprises 11 members with epilepsy, or the parents of children with epilepsy and 5 medical specialists. The rotation is annual. The board meets 13 times per year. There are no upper or lower age limits on membership.

## **INCOME AND EXPENDITURE**

Brainwave receives about £80,000 per annum through the European Social Fund (ESF). In 1998, it received funding from 7 of the 8 health boards - £36,900 from the Eastern Health Board, £5,000 from the North Eastern Health Board, £8,660 from the North Western Health Board, £4,000 from the Mid Western Health Board, £1,000 from the South Eastern Health Board, £5,000 from the Southern Health Board and £6,530 from the Western Health Board. Its FAS-funded CE scheme was worth about £70,000 per annum, although this has been reduced substantially in 1999. Brainwave relies on fundraising and charitable donations for approximately £230,000 per annum.

Its fundraising methods include special events, church gate collections, emblem sales, product sales, donations and corporate sponsorships. It hosts a *Horseshow Ball* in August annually, a national walkabout from May - August 1999 and a rose week in October each year.

### *Expenditure*

Brainwave spends about £220,000 on directly employed staff. Fundraising development and administration costs were £86,000 in 1998. Brainwave spent almost £90,000 on its training programmes in 1998. Its social work services cost almost £50,000. It has a research and development budget of almost £50,000 per annum. Its volunteer programme costs about £15,000 per annum.

## **STAFF**

Brainwave has a total of 20 directly employed staff, 3 of whom are administrative and 3 are fundraisers. A number of staff members work part-time. In all, 14 staff members have relevant or necessary qualifications.

### *CE scheme*

Brainwave's participation in CE schemes has fluctuated, with times when 12 CE workers were working with the association and other times when the CE complement was only 2. Brainwave has found the structure and operation of the CE schemes to have certain rigidities in relation to people with disabilities, particularly with regard to training and the length of time a person may remain on the scheme. It has also experienced difficulties in obtaining payments from FAS. Despite the difficulties Brainwave has had with CE, it has provided the association with

valuable options to carry out important tasks that would otherwise not be done. The success rate of placement of CE workers in direct employment is 85%.

#### *Volunteers*

Brainwave has about 60 volunteers, who fundraise for the association throughout the country. It also has a committee of about 25 volunteers who organise the *Horseshow Ball*.

#### *Training, monitoring and evaluation procedures*

Brainwave does not operate any accredited training programmes for staff or volunteers. It has in-house induction and training programmes for all categories of staff and volunteers. This includes modules on disability awareness and understanding epilepsy. Brainwave encourages its staff to attend external courses and has used the training offered by Disability Federation of Ireland (DFI), the National Social Service Board (NSSB), the Irish Union of Supported Employment, AHEAD (Association for Higher Education Access and Disability) and CNEASTA (the Irish council for training, development and employment for persons with disabilities).

Brainwave has no written guidelines on safety or complaints procedures. It is currently examining the many issues of concern in this regard. Brainwave has internal reporting mechanisms. Brainwave undertook the required EU Horizon project evaluations in 1997 and had an internal organisational evaluation in 1988.

#### **PREMISES**

Brainwave's national office is a 2-storey converted, private residence. It has no disabled access. Most staff have use of a dedicated computer. The offices have drop-in facilities and meeting rooms.

## **SERVICES**

#### **INFORMATION SERVICES**

Brainwave national office disseminates information by post, telephone and e-mail. This information covers a wide range of issues including common sense advice on how to assist a person who is having a seizure. Each of the 7 community resource officers/social workers in the health board regions provides information on request. Brainwave would like to have a freephone number but has not been successful in its application.

#### *Public awareness*

Brainwave has run a number of public awareness campaigns to inform the public about epilepsy. These have included poster campaigns. During the annual rose week, the association uses the surrounding publicity to give information about the condition. Brainwave has also produced information for employers on epilepsy in the workplace.

#### *Publications*

Brainwave produces leaflets, brochures and books on epilepsy and related topics. It also disseminates relevant information published by the British Epilepsy Association. It distributes a

CD-rom which has been produced by Glaxo Wellcome. It also has a videotape, although this now needs updating. The association publishes a quarterly newsletter, but does not have an annual report.

#### *Research*

Brainwave has undertaken some research on the topic of homelessness and epilepsy. It is also interested in a study of epilepsy and the elderly population.

#### *Plans for information services*

Brainwave is currently examining all aspects of its information service.

### **SUPPORT SERVICES**

Brainwave provides personal and family support services. The association encourages and enables support networks throughout the country. Brainwave is keen to develop the concept of specialist nurses for people with epilepsy. This has been a success in the UK and other European countries.

#### *Counselling service*

Brainwave provides professional personal, group and family counselling for people with epilepsy. It has a list of qualified counsellors throughout the country. It also has a crisis management intervention with onward referral to professional assistance.

#### *Aids and appliances*

Brainwave sells safety pillows, epilepsy bracelets and seizure diaries.

### **RECREATION SERVICES**

Brainwave provides limited social activities in the Dublin area. Social events may also be arranged through the branch network. Brainwave has undertaken holidays with young people through the EU Horizon projects.

### **VOCATIONAL/EMPLOYMENT SERVICES**

Brainwave is actively involved in informing employers about epilepsy. The association considers that many employers have outdated attitudes about the capabilities and appropriate work levels for people with epilepsy.

Brainwave operates 2 pre-employment courses for people with epilepsy. One is at Griffith College, Dublin and has 14 places. The other is at the Institute for Technology, Sligo and also has 14 places. Both courses include a work experience component. Brainwave conducts an extensive and intensive selection procedure which includes preliminary interviews, open days and use of a sampler course, all of which lead to final selection for the courses. Brainwave also assists in job placement after the course is completed.

## **ADVOCACY SERVICES**

Brainwave is committed to working for everyone with epilepsy in Ireland, their families and caregivers. It has ongoing contact with politicians. It sends information packs to all TDs and senators and MEPs. It has presented an information day at the Dail. Brainwave's main government department contacts are with the Department of Health and Children and the Department of the Environment. It has links with the Citizen's Information Centre (CIC) in Crumlin and gains access to information about entitlements and benefits through this source. It has strong inputs into the Joint Epilepsy Council of the UK and Ireland (JEC) and the International Bureau for Epilepsy (IBE) and stays abreast of legislative and social developments for people with epilepsy in Europe.

Brainwave conducts a number of campaigns on issues of concern to members. It presses for changes in the regulations on car driving for people with epilepsy. It also campaigns for a designated epilepsy centre, with a specialist epilepsy nurse. Brainwave encourages self-advocacy skills. It will also assist an individual with epilepsy to obtain services or entitlements.

# **CASA**

## **CARING AND SHARING ASSOCIATION**

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(01) 8725370

**Fax:** (01) 8725370

**Contact :** Martin Vaughan

### **INTRODUCING CASA, THE CARING AND SHARING ASSOCIATION**

CASA was founded in 1981 as a voluntary group dedicated to developing friendship between able-bodied and disabled members and to provide much needed social outlets for members with disabilities. Initially, CASA groups formed in Cork, Dublin and Longford. The organisation grew rapidly in the early years and at one stage more than 20 CASA groups operated in various locations throughout the country. In recent times, CASA has had difficulty sourcing and retaining volunteers. This has led to rationalisation of services in an effort to maintain standards. The main activities of groups include regular social events at local level, day trips, the use of holiday centres, pilgrimages to Lourdes and short-term respite breaks. In 1997, CASA purchased a house in Swords, Co. Dublin, which is available to CASA groups to provide short respite breaks for members. The association has set up charity shops to provide a dependable and regular source of income to fund its activities. CASA has also established a sister organisation, An Chlann. This involves full-time volunteers who provide week-long respite breaks in a family setting for people with disabilities.

A recent internal review will bring about organisational changes and CASA is keen to ensure that these are managed successfully. The association is currently drafting a mission statement which will reflect its core values of one-to-one service, friendship, spirituality and quality social gatherings. CASA identifies a number of main concerns at present. The economic upturn has made it difficult to attract volunteers. This difficulty in recruitment is amplified by the ever-increasing level of professionalism demanded of and within the voluntary sector. Fundraising is an ongoing challenge in the absence of permanent State aid.

## **MEMBERSHIP AND BOARD STRUCTURE**

CASA has a regional membership in Dublin, Cork and Longford. It has a branch network in Dublin in Avila (city centre) Ballygall, Berkeley Road, Drumcondra, Raheny, Blackrock, Crumlin, Greenhills, Harold's Cross and Kimmage. In Cork, branches are in Kinsale, the Lough, Mahon, Middleton, Turner's Cross, Wilton and Youghal. Other groups are in Bray, Co. Wicklow and in Longford.

CASA is a company limited by guarantee. CASA services are managed by committees for socials, meetings, administration, shops management, holidays and Lourdes pilgrimages. These committees are overseen by a central management committee which includes the chairs of the various activities committees. The central management committee members give a commitment to serve for a 2-year period. On average, the central management committee meets six times per annum.

## **INCOME AND EXPENDITURE**

CASA has an annual income of £250,000 approximately. Its main sources of income are from its group subscriptions to its Lourdes pilgrimages which provide about £90,000 towards the costs of the twice yearly expeditions. The CASA charity shops provide approximately £41,000 nett per annum. CASA also receives variable amounts from direct debit standing orders, administrative contributions from local groups, an annual plant sale, Christmas card sales, corporate and religious donations and funds from grant-aiding bodies. Local CASA groups raise funds through church gate collection and local events.

### *Expenditure*

The two visits to Lourdes annually cost approximately £100,000 in total. CASA spends about £27,000 per annum on its holiday provision. The CASA central administration funds cover various meeting costs, office rental, office operational and depreciation costs which run to approximately £57,000 per annum. Office staff costs are about £12,000 per annum. CASA owns and operates a minibus, which cost almost £40,000 to purchase and operate in its first year. CASA has had considerable set-up expenses for its charity shop ventures.

## **STAFFING**

CASA has a total of 6 staff members, 5 of whom work in the charity shops, while 1 staff member is a part-time office administrator. CASA also has access to a CE scheme operated through the Carmichael Centre, which provides the services of 2 CE workers. CASA participates and benefits from this scheme but is not directly involved in its administration. CASA has approximately 300 volunteers.

### *CE scheme*

CASA considers that the CE programme has been a valuable resource to the association and it has helped to develop and maintain the charity shop activities.

### *Training, monitoring and evaluation procedures*

CASA does not operate any accredited training programmes. Office staff and volunteers are encouraged to participate in relevant training courses organised by the Carmichael Centre.

CASA has a formal volunteer application and induction process, in line with practices recommended by Disability Federation of Ireland (DFI) and the Eastern Health Board (EHB). It involves an application form, the provision of two referees and a Garda clearance form. CASA requires an evaluation period of 3 months for all new volunteers to allow for induction and before a final decision is made on the volunteer's role in the organisation. CASA is currently reviewing its safety procedures through its administration committee. No formal complaints procedure is in place.

CASA undertook an internal organisational review in 1998/99. The outcome of this review is being disseminated to the membership and to families and guardians of members with disabilities. The review recommendations are due to be adopted formally in 2000.

#### **PREMISES**

CASA rents office facilities in the Carmichael Centre in Dublin 7 and benefits from the administrative pooling at the centre. These offices have drop-in facilities and meeting rooms available. CASA leases 6 shops. The association also owns a residential house in Swords, Co. Dublin, used for respite breaks. Local group activities take place in local community venues.

## **SERVICES**

#### **SUPPORT SERVICES**

CASA volunteers in local groups maintain regular contact by 'phone and by visiting members with disabilities and their families.

#### *Respite services*

A residential house in Swords, Co. Dublin is available to groups to provide short-term respite for members.

#### **RECREATION SERVICES**

CASA local groups organise regular (usually fortnightly) social events, nights out, day trips etc. for members. Week-long holidays are provided in July of each year. CASA also organises two groups per year to visit Lourdes. One of these is confined to CASA members. The other is open to nonmembers with terminal illness and their family members.



# CENTRAL REMEDIAL CLINIC

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Website: [www.crc.ie](http://www.crc.ie)

Chief Executive: Paul Kiely

## INTRODUCING THE

### CENTRAL REMEDIAL CLINIC

The Central Remedial Clinic (CRC) was established in 1951 by Lady Valerie Goulding. The clinic sought to provide aftercare treatment to people with poliomyelitis, following its outbreak in Dublin in the 1940s and '50s. In 1968, the CRC moved to its present premises on the north side of Dublin city. Today the clinic is the largest national centre in Ireland for people with physical disabilities and provides a range of services to about 3,000 children and 500 adults annually.

The CRC has a mission statement which reflects the clinic's ethos in helping people with disabilities to take responsibility for their lives and to set and achieve their own goals. Deriving from this mission statement, the clinic has also laid out a statement of objectives. These focus on the agreement of the clinic to standards of service, of liaison, of responsibility and ethics. The CRC identifies some of the significant developments in the past 10 years as the development of its gait laboratory, its vocational training programmes and its technical division.

## MEMBERSHIP AND BOARD STRUCTURE

The CRC is not a membership-based organisation. The CRC has a Parents' and Friends' Association, which was formed in 1965. It holds regular meetings and promotes informal contacts and fundraises. Scoil Mochua, in Clondalkin, also has a Parents' and Friends' Association. The CRC is a company limited by guarantee. Its charity number is CHY: 4998. It has a board of 13 governors. It also has a management committee comprising the chief executive, medical director, administrator and the managers of its main services. The 2 schools in Dublin operate under the patronage of the clinic. Both schools have boards of management and are operated under the Department of Education and Science.

### CENTRAL REMEDIAL CLINIC OUR MISSION

We are people concerned about the well-being, happiness and achievements of people with disabilities and the welfare of their families, advocates and supporters.

Our key aims are to help people with disabilities: to take responsibility for and have control over their own lives and; to set and achieve their own goals.

We seek to achieve our aims by assessing, consulting, treating, educating, developing and supporting people to the best of our abilities. We also seek to understand, anticipate and respond to their needs in a timely and efficient manner.

We try to do our daily work in a consistent, friendly way and to discuss issues openly, in a spirit of partnership, with the people we seek to serve.

## **INCOME AND EXPENDITURE**

All figures presented here are from the 1998 financial statements. The CRC had a turnover of £6m. in that year. European Social Fund (ESF) income came to £ 385,000 per annum. The main source of income was from the Department of Health and Children. Additional income came from various operating revenue grants, including the Eastern Health Board (£637,000), the North Western Health Board (£6,000) and the Department of Education and Science (£169,000 for schools) and additional fundraising income. Although the clinic is largely funded by the State, a significant shortfall must be made up by voluntary donations and fundraising. These additional funds play a vital role in the upkeep and survival of the clinic and help to ensure that its services remain free of charge.

## **STAFF**

The CRC has a total staff complement of 187, including temporary and part-time staff and contractual workers.

### *CE scheme*

The CRC has a CE scheme currently scheduled to employ 27 workers and 1 supervisor.

### *Volunteers*

The CRC has more than 100 volunteers. The personnel department recruits, trains and deploys volunteers. The clinic has extensive links with voluntary leisure services in the community and encourages participation of young people in suitable community-based activities.

### *Safety and monitoring procedures*

The CRC has written safety, complaints and internal reporting mechanisms. The clinic staff are trained in safe handling and in privacy issues when assisting people with disabilities in intimate tasks.

## **PREMISES**

The CRC provides its main services in a modern building in Clontarf. Services are provided on an outpatient basis. The building is completely accessible. The building also has a "Parents' and Friends'" room where parents hold regular meetings. The clinic also provides an extensive catering service providing meals for children attending the clinic, service users and their carers, workshop employees, course participants and general staff.

# **SERVICES**

## **INFORMATION SERVICES**

The social work department of the CRC provides a full range of information on statutory entitlements, medical card applications, home care assistance and respite services. Each department provides information on its own services. The CRC publishes a range of information booklets on each of its services and a book describing its activities.

### *Public relations*

The public relations and fundraising department at the CRC is responsible for heightening public awareness of the clinic, both at home and abroad. It aims to create a better understanding of the organisation amongst its many interested constituents and stimulates support for the clinic in all its activities.

### *Research*

A Research Trust was established by the CRC in 1971 and its funding focuses on solving problems associated with physical disability. The psychology department at the CRC has conducted research in the area of perception in children with minimal physical disabilities. Other departments conduct research projects from time to time.

## **EDUCATION SERVICES**

The CRC operates 2 schools for children aged 3 - 18 years under the Department of Education and Science. Each child follows an individual educational programme. Therapy services are available to the children during school hours. Both schools actively encourage the participation of parents.

The Clontarf school caters for children from the north city and county of Dublin. It provides a full range of services including free school transport, meals and medical services. The school provides formal tuition to Junior Certificate standard. Swimming and riding are available to students. The school has close links with local secondary schools.

Scoil Mochua, in Clondalkin caters for children and young people from west Dublin, Kildare and west Wicklow. The school has an observation/diagnostic unit assess and monitors the progress of individual children. Scoil Mochua provides support to students and to parents and prospective teachers to enable them to complete their education in local schools.

### *Educational technology support service*

The CRC runs a support service for teachers in the use of educational technology with children and young people with disabilities. This service is funded by the Department of Education and Science.

## **MEDICAL/NURSING/THERAPEUTIC SERVICES**

### *Medical services*

Medical services of diagnosis and treatment are provided by specialist paediatricians, orthopaedic surgeons and vision and hearing specialists.

### *Nursing services*

The nursing department at the CRC promotes preventive healthcare and education. It also provides direct nursing services when necessary and provides programmes of support for families.

### *Therapeutic services: physiotherapy*

The CRC has the largest paediatric physiotherapy unit in the country. The adult physiotherapy unit provides a community service for people living on the north side of Dublin. The CRC has a specialised hydrotherapy facility, used mainly by adults. The CRC also has a gait analysis laboratory, one of a few in Europe and the first of its kind in Ireland. It was established in 1990 to assess the walking ability of people with physical disabilities. It is also used to test the effectiveness of physiotherapy, orthotics and surgical procedures.

### *Therapeutic services: occupational therapy*

The occupational therapists seek to assist children and adults to develop and maintain independence in daily living tasks. Initial assessment may take place as young as 6 months.

### *Seating department*

The CRC has a seating department which provides individualised seating and positioning systems for people with physical disabilities. It also modifies and adapts seating systems and wheelchairs with accessories such as straps, harnesses, arm rests, foot rests and head supports.

### *Therapeutic services: speech and language therapy*

Speech and language therapy at the CRC focuses on early intervention. Alternative and augmentative communication systems are taught and used in daily life. The speech and language therapy department also runs regular feeding clinics to assist individuals with feeding difficulties.

### *Dietetics services*

The dietetics department provides a clinical and advice service to people attending the CRC. Staff give talks and lectures on diet and the dietary needs of children with physical disabilities.

### *Psychology services*

The psychology department provides the full range of assessment, therapy and counselling services. Consultation and advice are provided to Muscular Dystrophy Ireland, the Cheshire Foundation and the Center for Independent Living.

### *Social work services*

The CRC social workers seek to ensure family and social support for each child or adult with a disability.

### *Assistive technology/technical division*

A team including a rehabilitation engineer, technicians and a variety of qualified therapists and teachers seek to identify the technology assistance best suited to each individual referred to the service. This service is particularly important in designing appropriate communication aids.

This division is involved in a range of transnational research and development projects and actions. These include APHRODITE (A Partnership to Harness Resource Opportunities and Distribute Information Technology Expertise) conducted under the EU Horizon programme between 1997-1999. Another project is ICAN, (Integrated Control of All Needs), conducted under the EU TIDE programme. This project began in May 1998 and is scheduled to run for 36 months.

## **SUPPORT SERVICES**

### *Day activity centres*

The CRC manages 4 day activity centres in Clontarf, Coolock, Firhouse and Hartstown, in cooperation with the Eastern Health Board. Members attend 2/3 times per week, usually in groups of similar age or interests and participate in a range of activities including creative writing, crafts, artwork, cooking reading, computer games, drama quizzes and yoga. The CRC plans a new day activity centre north Dublin.

### *Support groups for parents*

The CRC's social work department has a number of support groups for parents.

### *Counselling services*

The psychology department of the CRC offers counselling and therapy services for individuals, siblings, families and groups.

### *Visiting services*

Many different staff members visit the client's home for assessment and therapy purposes.

### *Home support/respite services*

The CRC's social work department provides a limited family aid service. This involves a family aid worker visiting a child in his/her own home for a half or full day per week to take over the care of the child.

### *Transport services*

The CRC has a fleet of 10 ambulances and a taxi service. These go to provide transportation for approximately 200 service users on a daily basis.

### *Catering services*

The CRC provides an extensive catering service for children and adults attending the clinic, parents and other visitors, staff and volunteers.

### *Equipment purchase or loans*

The occupational therapy, physiotherapy and speech therapy departments can provide necessary equipment on loan.

### *Plans for service development*

The CRC is committed to the regionalisation of its services.

## **RECREATION SERVICES**

### *Day activity centres*

People attending any of the 4 day activity centres in Clontarf, Coolock, Firhouse and Hartstown may participate in the recreation activities programmes.

### *Holidays*

The day activity centres organise regular day trips and holidays.

## **VOCATIONAL/TRAINING AND EMPLOYMENT SERVICES**

The CRC offers a range of training and employment services to adolescents and adults.

### *Pre-vocational training service*

The CRC operates 2 vocational training courses funded by the European Social Fund (ESF) and the Department of Health and Children to provide opportunities for young adults who have left school. Both courses are certificated and have extensive links into the local community.

Skill base Level 1 provides young adults with disabilities with work and related skills including retail sales experience, computer training, job seeking, catering and independence skills. Each trainee is awarded a certificate of achievement on completion of the programme.

TOPS is a programme of personal and practical skills to develop independence in the home and encourage integration in the local community while identifying skills needed for supported employment. Each trainee is awarded a certificate of achievement on completion of the programme.

### *Work orientation service*

The CRC provides work orientation training for up to 24 young school leavers aged 18-21 years.

### *Computer training service*

Young people can train in desktop publishing and in-plant printing to City and Guilds certification with a view to working in mainstream or supported employment. These courses are supported by ESF funding.

### *Employment placement service*

This provides support to adults seeking employment.

### *Supported employment service*

The CRC provides workshop rehabilitation and supported employment in an industrial setting to almost 100 people with disabilities. Work includes commercial printing, desk top publishing, and the manufacture of handmade and other craft items.

## **ADVOCACY SERVICES**

The CRC seeks to promote the needs and aspirations of people with disabilities attending its services. It lobbies the Departments of Health and Children, Education and Science and Justice, Equality and Law Reform on a variety of issues in relation to national policy and service delivery. It has an involvement with the National Rehabilitation Board in connection with its vocational and employment services and seeks to develop and implement best practice in the context of European and Irish standards. The social work department of the CRC provides an advocacy service for clients to other professionals and agencies such as housing authorities, residential units and respite facilities.

# CEREBRAL PALSY IRELAND (CPI)

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Chief executive officer: Michael W. Cummins

National development manager:  
Ruaidhri O'Connor

## INTRODUCING CEREBRAL PALSY IRELAND (CPI)

Cerebral Palsy Ireland (CPI) was founded in 1948. In 1951, the organisation moved into its premises on Sandymount Avenue, Dublin 4. It pioneered the establishment of special schools for children with cerebral palsy, the first of which was sanctioned by the (then) Department of Education in 1952. Nowadays, it provides medical consultancy, assessment and rehabilitation centres, educational, vocational, independence and advocacy services for children and adults with physical disabilities resulting from cerebral palsy, spina bifida, hydrocephalus, muscular dystrophy and other disabilities. CPI services are provided in 10 counties of Ireland in 6 health board regions. There are substantial variations in the range and types of services on offer in different regions. The aim of CPI is to enable individuals using the services to achieve maximum independence, choice and inclusion in their communities. CPI seeks to develop its services in active partnership with its service users and with the statutory authorities.

## MEMBERSHIP AND BOARD STRUCTURE

CPI has a national membership of circa 2,300. CPI has branches in Cavan, Clare, Donegal, Galway, Kerry, Kildare, Kilkenny, Limerick, Longford, Louth, Mayo, Meath, Monaghan, north Tipperary, Offaly, Roscommon, Sligo, Waterford and Wexford.

CPI is a company limited by guarantee. Its charity number is CHY: 4908. The executive board of CPI comprises 9 members. The rotation of board membership is every 3 years. The board holds 6 meetings per year. There is no lower or upper age limit on board membership. Services are provided to nonmembers.

## CEREBRAL PALSY

Cerebral palsy is a problem which affects 4-5 in every 2,000 children in Ireland. It is a disorder of movement and posture caused by a non-progressive defect of the immature brain. In most instances, the cause of cerebral palsy occurs before birth, although sometimes it happens during or after birth.

There are 3 main types of cerebral palsy which give rise to stiff or uncontrolled or unsteady movement. Each person with cerebral palsy has individual abilities and difficulties. Some people with cerebral palsy may have some degree of learning disability.

Positive intervention should begin as soon as the condition is evident. This involves the physiotherapist, occupational therapist and speech and language therapist in particular. Children with cerebral palsy benefit from specialised teaching. Many people with cerebral palsy lead independent lives which include employment, recreation and social involvement, sometimes with personal assistance.

## **INCOME AND EXPENDITURE**

In 1999, funding of £6m was provided by statutory sources and another £1.5m was obtained through fundraising and a carry-over deficit. In 1999, it cost CPI circa £7.5m to provide services.

## **STAFF**

CPI employs more than 300 people, including medical directors, physiotherapists, occupational therapists, speech and language therapists, social workers, psychologists, preschool leaders, teachers, child care workers and administrative and support staff.

### *CE scheme*

CPI operates CE schemes which involve 155 workers. These schemes have assisted CPI in pioneering new services and in supporting existing services. About 10% of CE workers go on to mainstream employment.

### *Volunteers*

CPI actively seeks volunteers for its activities. It advertises for volunteers for its centres, charity shops and for other fundraising ventures on its website.

### *Training, monitoring and evaluation procedures*

Staff have opportunities to attend professional and other courses. CPI operates an induction process for new staff. CPI has written safety, monitoring and reporting procedures. CPI undertakes regular internal reviews of all of its services.

## **PREMISES**

CPI has a large number of premises. The Sandymount complex comprises children's and adults' day services, a hydrotherapy pool, a seating clinic, a special school with 7 classrooms, a workshop and a training/community resource service for adults.

At Bray, Co. Wicklow, the CPI Marino Clinic is a large house with school and children's services and residential/respite facilities. In Cork, CPI services are available at the Lavannagh Centre. This is a large, purpose-built facility which includes consulting and therapy facilities and a special school. The CPI Kilkenny centre, the CPI centre at Mungret, Co. Limerick and the CPI Galway centre are all purpose-built facilities.

## **SERVICES**

### **INFORMATION SERVICES**

Nationally, CPI provides its service users with information on cerebral palsy and other conditions, on social welfare and other entitlements. The social work departments of the various centres give personalised information to clients.



### *Media campaigns*

CPI's annual *yellow ribbon* week is a fundraising event which provides opportunities for media exposure. CPI uses its clothing recycling bank scheme and its shops as means of raising public awareness of the organisation.

### *Publications*

CPI publishes an annual report. CPI has an informative and interactive website.

### *Research*

CPI commissions research from time to time. At its Cork centre, it undertakes direct research on an ongoing basis.

## **EDUCATION SERVICES**

### *Preschool services*

Preschool services are available in 7 of the CPI centres: Sandymount, Tallaght, Wicklow, Cork, Galway, Kerry and Limerick. Some specialised therapeutic support, both centre-based and home-based, is on offer to children who attend mainstream early education in these locations. Support to enable a given child with cerebral palsy to go to a mainstream school is also provided.

### *Special schools*

CPI operates 3 special schools in Sandymount, Wicklow and Cork. These provide services to children between the ages of 5-18 years. During the school day, the children and young people may obtain therapy and other support services. Older students receive vocational guidance and counselling services. Pre-vocational services in preparation for post-school employment placement are also available.

### *Sensory integration programme*

Specialised assistance in the form of a sensory integration programme is available for children with coordination, sensory and motor difficulties in Sandymount, Kerry and Bray, Co. Wicklow.

## **MEDICAL/NURSING/THERAPEUTIC SERVICES**

CPI's child and family services include medical, paramedical and other specialist assessment.

### *Early services programme*

CPI operates an early services programme in Sandymount, Tallaght, Wicklow, Cork, Galway, Kerry and Limerick. This involves an interdisciplinary team, working in partnership with the families and children, to help the child achieve in every aspect of their development.

### *Specialised services*

CPI offers hydrotherapy at Sandymount, Kilkenny and Cork. It has an orthotics service at Sandymount and in Limerick. It runs a seating clinic at Sandymount.

In Mayo, CPI provides an outreach physiotherapy service at 3 locations throughout the county with a special transport service to and from these centres. The Mayo CPI group also provides hydrotherapy swimming sessions.

The CPI centre in Kildare provides a specialist physiotherapy service to children with physical disabilities living in the county. CPI plans to provide a full range of services at the Kildare centre from 2000 onwards.

#### **SUPPORT SERVICES**

CPI offers a wide range of support services through its large and qualified professional staff. Branches and centre staffs organise parents' support groups and parent and toddler groups. Families may obtain social work support and parent skills' development programmes

##### *Day services*

CPI provides a day service for adults with significant physical disabilities through its Mungret, Co. Limerick centre. CPI also provides support to an adult day centre run by the Western Health Board in Loughrea, Co. Galway.

##### *Counselling services*

CPI has a team of trained professional psychologists and social workers who offer a range of counselling services to children and adults with cerebral palsy and other conditions, to parents and couples and to siblings.

##### *Respite services*

Home-based respite is available through CPI's centres in Dublin, Wicklow, Cork, Kerry, Limerick, Clare, Galway and Mayo. CPI offers holiday respite accommodation in a number of its locations namely, Sandymount, Wicklow, Limerick, Clare, Cork, Galway and Tallaght.

#### **RECREATION SERVICES**

CPI offers sporting activity through most of its centres.

#### **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

CPI provides pre-employment courses at its adult service locations in Dublin, Cork, Kerry and Limerick. CPI operates a range of European Union (EU) funded employment projects in Dublin, Cork and Clare. It also runs a small sheltered workshop programme in Dublin.

#### **HOUSING SERVICES**

Residential accommodation in a community setting is available in Bray and Cork for a small group of children attending special schools at these locations.

### **INDEPENDENCE SERVICES**

CPI runs personal development programmes for people with cerebral palsy to promote independent living skills and opportunities. It provides personal assistance to adult service users at all service locations. It will provide support for adults attending training courses provided through other agencies.

### **ADVOCACY SERVICES**

CPI seeks to act as an advocate for people with cerebral palsy and their families. It is active in lobbying central and regional government agencies to improve the availability and standards of services nationally. It has ongoing contact with the Department of Health and Children. It seeks partnership with the health boards in providing services on local and regional bases. It is critical of existing State spending levels on services. It is an active member of Disability Federation of Ireland (DFI).

## CO. ROSCOMMON SUPPORT GROUP OF PEOPLE WITH DISABILITIES

Address: Resource Centre  
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Co. Roscommon

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Fax: (0903) 25960

Information centre:  
Castle Street  
Roscommon town  
Co. Roscommon

Tel: (0903) 25172  
Fax: (0903) 25879

E-mail: rdsg@iol.ie

CIL programme manager: Mary Ganley  
EU Horizon project coordinator: Antoinette  
Garvey

### INTRODUCING CO. ROSCOMMON SUPPORT GROUP OF PEOPLE WITH DISABILITIES (RSG)

The RSG was established in 1989 and seeks to assist people with disabilities in Co. Roscommon to live independent and productive lives. The stated objective of the group is to empower and enable people with disabilities to achieve independent living. One of the means the group employed was the establishment of a Center for Independent Living (CIL) which then commenced a personal assistant (PA) service through the FAS CE programme.

The group is also actively involved in a European Union (EU) Horizon-funded training project which is run jointly with the Irish Wheelchair Association and the Brothers of Charity. As part of this project, the RSG seeks to provide information, advice and support to people with disabilities their families and friends. It also seeks to raise public awareness about the needs of people with disabilities living in Co. Roscommon. It provides basic training in computer and office skills.

The RSG's funding is almost entirely project-based. This has meant that the group has been unable to develop core services and has no core staffing. The group is seeking alternative ongoing funding of the PA and vocational services as a matter of urgency. In the longer term, the group wishes to secure funding to enable people with disabilities to train as resource

### LIVING WITH A DISABILITY IN RURAL IRELAND

In the past decade, people with disabilities have joined together to present a united voice which argues for inclusion of people with disabilities in society at large. This campaign seeks disabled access to the range of opportunities and resources that able-bodied people take for granted. It seeks change in society's perception of what is appropriate for all its members, regardless of where they live.

People with disabilities living in rural Ireland are confronted by numerous obstacles in their search for a full life. Educational opportunities may pose problems for people living in remote areas. Distance learning, a development of great practical value to people with disabilities, may not be a possibility due to lack of family resources to purchase a computer and the necessary software.

The absence of accessible transport confines people with physical disabilities to their homes. If people cannot get to education, training, work or recreation, they are effectively excluded from the lifestyle expected and enjoyed by able-bodied people. The opportunities for people with physical disabilities living in rural Ireland now lag behind those of their peers in the cities.

workers and to provide employment for people with disabilities in the county. It would also like to develop the PA service, which has a lengthy waiting list and to increase its existing physiotherapy service for people with multiple sclerosis.

#### **MEMBERSHIP AND BOARD STRUCTURE**

The RSG has no formal membership. It is a company limited by guarantee. Its charity number is CHY: 231700. The board comprises 9 members, with an annual rotation and holds 9 meetings per annum. In all, 3 of the board members are people with disabilities.

#### **INCOME AND EXPENDITURE**

The CIL FAS-funded CE scheme costs £80,000 per annum. The RSG has received £62,000 to date from the EU Horizon programme. This project will cease in March 2000. In 1998, the support group had a total core income of almost £17,000. Of this, £4,000 was obtained from the Western Health Board, £3,716 from the Roscommon Partnership and £4,000 from the People in Need trust. The support group runs a number of fundraising events including participation in the mini-marathon (June), church gate collections (August) and pub quizzes (October). The Western Health Board also provides the services of a sessional physiotherapist, on a fortnightly basis.

#### *Expenditure*

The RSG spent almost £13,000 in 1998. The main expenditure was on equipment and maintenance of its office.

#### **STAFF**

The RSG has no directly employed staff. The CIL operates a FAS-funded CE scheme with 11 CE workers, 1 of whom is a programme manager. The Horizon project employs a part-time coordinator and 2 part-time information officers. The RSG also has 20 volunteers who undertake home visits in the area.

#### *CE scheme*

The role of the CE scheme is crucial to the existence of the support group. The support group considers that the mainstream employment placement rate for ex-CE workers has been excellent and notes instances where CE workers have found full-time employment in nursing homes and in government departments.

#### *Training, monitoring and evaluation procedures*

The RSG operates accredited training programmes for CE workers. The group operates additional in-house induction and training programmes for CE workers with an emphasis on the philosophy of independent living. The group sees value in developing additional accredited training programmes. The group has written safety procedures for its CE staff, including formal complaints procedures and internal reporting mechanisms. The RSG has no volunteer recruitment or retention strategies and has no volunteer safety or monitoring protocols.

The group has never undertaken an independent organisational or service user evaluation. It has sought funds for the latter, but was unable to secure any. The group has never undertaken an internal organisational evaluation. The EU Horizon project evaluations have been completed as required by contract.

#### **PREMISES**

The RSG has offices in a resource centre which was made fully accessible through voluntary work and funding from People in Need, the Western Health Board and other statutory agencies. The group uses 2 computers. The centre offers drop-in facilities, meeting rooms and a counselling room. The EU Horizon project has offices in the Citizen's Information Centre (CIC) at Castle Street, Roscommon town. These offices are also fully accessible.

## **SERVICES**

#### **INFORMATION SERVICE**

The RSG provides an information service to people with disabilities from the Citizen's Information Centre (CIC) at its Castle street office in Roscommon town. This service provides free and confidential information on all aspects of disability, health and social welfare entitlements and refers queries about other issues to the appropriate source in the CIC. People making enquiries are assisted in filling out social welfare forms etc. The support group also gives talks on disability to interested groups, mainly schools.

#### *Publications*

The RSG produces an annual report. It also has leaflets describing the various services it offers.

#### *Research*

The CIL of the RSG has undertaken action research. It investigated the disabled access of public buildings in Roscommon town. This activity led to improved access for disabled people to one of the local banks.

#### **EDUCATION SERVICES**

In 1998-9, 13 members of the group participated in a pilot scheme, operated by Dublin Center for Independent Living (CIL). This was an educational programme with a formal course on disability studies, accredited by the National University of Ireland (NUI), Maynooth. The RSG also assisted in setting up sign language classes in the local Vocational Educational Committee (VEC). The RSG is eager to respond to educational needs of people with disabilities, their families and caregivers. Lack of resources precludes the development of such a response.

#### **THERAPEUTIC SERVICES**

The Western Health Board provides a physiotherapist who attends the resource centre on a fortnightly basis to provide treatment for people with disabilities in the area. The RSG would like to expand this service.

## **SUPPORT SERVICES**

The RSG is a support network for people with disabilities and provides informal support contact for individuals and families. Volunteers visit people with disabilities throughout the county and encourage them to become involved in existing services. They also give peer support to people newly diagnosed with multiple sclerosis and other serious medical conditions.

### *Peer counselling service*

The RSG provides a peer counselling service by disabled people for disabled people. This is both centre-based and outreach. The support group has plans for the expansion of this service but lacks the transport to put the plan into action. Formal counselling services are available to people with problems through the Family Life Centre in Boyle.

## **VOCATIONAL/TRAINING SERVICES**

The RSG provides training in conjunction with the EU Horizon employment programme. This project, called RESET, involves 4 people with disabilities who are learning basic computer and office skills. They are also given assistance in the preparation of their CVs and in the development of interview skills through job coaching. It is hoped that participants will gain employment from the project.

## **INDEPENDENCE SERVICES**

The RSG operates a personal assistant (PA) service, with CE staffing of 10 personal assistants, giving 10 people with physical disabilities approximately 20 hours each of personal assistance. This scheme is extremely popular. It has a waiting list of about 35 individuals.

At present, the group is designing a service plan for presentation to the Western Health Board for the provision of a personal assistant/home support service in the region. The RSG wishes to assist young people who are unable, or not ready, to live alone to achieve greater physical independence in their family homes.

## **ADVOCACY SERVICES**

The RSG has contact with politicians, health board administration and the government Departments of Health and Children and Education and Science. The group meets with the Irish Council of People with Disabilities (ICPD) on a monthly basis and 2 of the members of the RSG are on the local committee of the council. Two members of the group are on the health board coordinating committee.

The RSG is developing organisational links with the National Rehabilitation Board (NRB), the National Social Services Board (NSSB) and with local information and support services in order to develop awareness of the needs of people with disabilities living in Co. Roscommon.

# CYSTIC FIBROSIS ASSOCIATION OF IRELAND (CFAI)

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Chief executive: Larry Warren

Adult services: Fiona Purcell

## INTRODUCING CYSTIC FIBROSIS ASSOCIATION OF IRELAND (CFAI)

The Cystic Fibrosis Association of Ireland (CFAI) was founded in 1963. It is the national body which aims to promote medical research and to provide support services for children and adults with cystic fibrosis (CF) and their families. It sees itself mainly as an advocacy group. CFAI

identifies its lung transplant campaign, its involvement in improving the health status of individuals with cystic fibrosis through research and its cyber campus for young adults with cystic fibrosis as the main achievements of the organisation in the past 10 years. CFAI's next focus is to gain acceptance and cooperation for its proactive paediatric policy which calls for a national neonatal screening for cystic fibrosis and an intensive therapeutic regime for all children diagnosed, in order to increase life expectancy and quality of life. This policy includes a CF national shared care network, development of adolescent and outreach services, a CF register/database for Ireland and a CF information unit. CFAI is working in partnership with the Department of Health and Children and the health boards to achieve these goals.

## MEMBERSHIP AND BOARD STRUCTURE

The membership is approximately 1,500, comprising the 900 individuals and families affected by the condition, friends, interested medical, paramedical and nursing professionals. Members form 22 branches throughout the country. These branches are grouped into 8 regional structures in the health board regions. The organisation holds a 3-day annual conference.

CFAI is a company limited by guarantee. Its charity number is CHY: 6350. It has two distinct organisational structures. One is a national executive committee, which meets 6 times per year and has 20 members, elected representatives from each of the regions. To date, rotation of council membership has been limited, with no upper age limit. The other is a medical and scientific council, which meets 4 times per year. It is composed of experts in the management of

## CYSTIC FIBROSIS

Cystic fibrosis (CF) is the most common inherited, life threatening illness. Ireland has the highest proportion of people with CF in the world. More than 900 people live with CF in Ireland. The condition is genetically inherited and 1 in 20 of the Irish population carries the gene for CF.

CF affects the glands, damaging many organs including the lungs, pancreas, the digestive tract and the reproductive system. People with CF are prone to constant chest infections and to malnutrition.

At present, treatment consists of drugs, enzymes, physiotherapy, vigorous exercise and control of diet. Many people with CF lead near-normal lives. Some people need lung transplants, often in early adulthood.

There is no cure for CF but the future holds prospects for improved drug therapy and, in the longer term, a genetic therapy.



cystic fibrosis and officers of the national executive and acts as an advisory body to CFAI. All of CFAI's services are available to any person with cystic fibrosis or any family member.

#### **INCOME AND EXPENDITURE**

In 1998, statutory funding of CFAI came in the main from health boards whose contributions amounted to £37,583.40 (Eastern Health Board £7,870, Midland Health Board NIL, Mid Western Health Board £16,963.40, North Eastern Health Board £3,000, North Western Health Board £3,750, Southern Health Board £3,000, South Eastern Health Board £3,000, Western Health Board NIL). In 1998, a total of £4,000 was obtained from the Independent Living Fund. FAS supports 2 CE workers at CFAI.

CFAI is almost entirely dependent on fundraising, donations from the general public, income from its shops and from local branches and from altruistic business interests. The main means of fundraising for CFAI are from local branches through church gate collections, from sponsorships and other charitable activities and from national fundraising campaigns such as Sail around Ireland and Cycle across Ireland and international walks. CFAI runs a charity shop at 142, Capel Street, Dublin 1. CFAI intends to launch a national doll day for cystic fibrosis awareness and fundraising. Income from CFAI charitable and commercial activities in 1998 amounted to £236,482 before deduction of relevant expenses. This sum included £21,512 from Christmas card sales and £34,481 gross from charity walks. Its golf classic raised £26,000 gross, sponsorship in the women's min-marathon produced £19,395 and other sponsored events gave £52,758 in total. Branch donation to CFAI was £189,785 for the year.

#### *Expenditure*

In 1998, CFAI spent £482,925 on all of its services. Overhead expenditure came to £212,296, including £92,320 on staff wages and salaries. Its various fundraising activities necessitated the expenditure of £90,039. The organisation spent £53,118 on its home-based physiotherapy service and £62,190 on research activities. CFAI part-funds, from its own organisational funds, a trained counsellor in St. Vincent's Hospital, Elm Park, Dublin, and nurses and physiotherapists at Cork University Hospital, Castlebar Regional Hospital, Our Lady's Hospital for Sick Children, Crumlin and Beaumont Hospital. CFAI provided £24,539 to enable young people with CF to obtain heart-lung assessments with a view to transplant. The association provided £5,599 in necessary equipment and £6,162 was allocated to families/individuals in distress.

#### **STAFF**

CFAI employs 5 staff and 2 CE workers. All staff have relevant qualifications. CFAI operates a liaison officer scheme through its branch network, which involves the appointment of a branch contact person who provides information and support to individuals and families in the branch area. The costs for this were £8,369 in 1998. The total number of CFAI volunteers is large but unknown and is concentrated in the local branches. The volunteer involvement is not costed, but is minimal.

### *Training and monitoring procedures*

All staff are enabled to attend appropriate external training courses, including professional qualification courses. CFAI has no internal training schemes or induction programmes. Internal reporting mechanisms are developed. The role of CE gives good training for the organisation.

### *Evaluation procedures*

CFAI has yet to undertake an independent organisational or service user evaluation. It has conducted internal service user evaluations and responded to the results.

## **PREMISES**

CFAI is situated in a 2-storey terraced building with limited drop-in facilities and meeting rooms and no disability access or hygiene facilities. The premises are due for renovation in 2000.

## **SERVICES**

### **INFORMATION SERVICES**

#### *Information to members and families*

CFAI provides an information service immediately on diagnosis and contacts each member/family bimonthly from that point on. It provides information on the genetic centre in Our Lady's Hospital for Sick Children, Crumlin, Dublin 12 and will assist in obtaining appointments.

#### *Information to the public*

CFAI runs public campaigns, sends literature to schools, participates at public meetings and at conferences. It promotes its agenda in the media, in particular to develop and sustain its lung transplant services campaign.

#### *Publications*

CFAI publishes an annual report, an annual newsletter, a bimonthly newflash and a quarterly magazine *Future force* written by members, the format of which will be upgraded in the next year.

#### *Research*

Research is one of the main focuses of CFAI. Its medical and scientific council examines research applications on a three yearly basis and selects a small number (about 5) for core funding. The budget for this is approximately £70,000 per annum. CFAI has also published a number of social research reports from investigations of its members' needs (see independence services below).

### **EDUCATION SERVICES**

CFAI operates a cyber campus, an online computer training course. This course has, primarily, an educational focus, but also acts as a social contact between students. It is focussed on early school leavers and on people whose education has been disrupted through frequent hospitalisation. It is home-based and is available nationwide. It involves 2 of CFAI's trained

staff on a part-time basis. In addition, CFAI employs 12 tutors, on contract, to provide the course content. At present 28 students are on the programme. There is a waiting list. The process of selection is lengthy and detailed and involves filling out a questionnaire, attendance at a seminar and personal interview. CFAI initially obtained EU Horizon funding for this project. Telecom Eireann has supported the project with free internet on-line time worth approximately £20,000. Some corporate bodies have donated computer hardware. This service was independently reviewed in 1998 and is reviewed internally in CFAI on a regular basis.

#### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

CFAI sees itself as a partner in the provision of services to people with cystic fibrosis.

##### *Nursing services in regional hospitals*

CFAI has set up nursing services for people with cystic fibrosis in 10 of the main regional hospitals. This nursing service is initially funded by CFAI and is then paid for in full by the relevant health board. For 1999, CFAI intends to establish 4 new CF nursing posts in Tralee, Beaumont, Castlebar and in Cork for the adult unit. These nurses organise the CF clinics, provide a direct medical interface with individual with CF and liaise with CFAI national office. CFAI is committed to improving nursing outreach services nationally.

##### *Domiciliary nursing services*

CFAI provides home-based nursing services on request to its membership, to assist during bouts of serious illness. CFAI will provide a palliative nursing service, where possible.

##### *Domiciliary physiotherapy services*

Every child with cystic fibrosis requires daily intensive physiotherapy. This is provided by the parents. CFAI provides a home-based physiotherapy service from the time of diagnosis to train the parents, with a review one year after diagnosis and additional intervention when the individual with cystic fibrosis begins to learn to treat him/herself. CFAI has a written *National domiciliary physiotherapy policy* which outlines the operation of this service. CFAI has a register of 20 qualified physiotherapists located throughout the country who provide home visits to families. CFAI pays for these visits on a fee basis. About 100 individuals with cystic fibrosis avail of this service each year. There is no waiting list and people in need of the service identify themselves. CFAI has reviewed this service internally. It found that the service was unsatisfactory, as there are areas in the country where qualified physiotherapists are not available. As such, it is an incomplete service, lacking in equity and accountability to the appropriate medical professionals.

##### *Financial assistance to attend specialist services abroad*

CFAI provides financial and organisational assistance to approximately 30 families per year to attend medical specialist units in Great Britain, primarily in connection with assessment for suitability for lung transplants.

##### *Plans for medical/therapeutic services*

CFAI intends to continue and to expand its involvement with hospitals to partner CF clinical development. It seeks to ensure the best international standards service will be available to people with cystic fibrosis in Ireland.

## **SUPPORT SERVICES**

All of the branches provide informal support to members when newly diagnosed and at times of difficulty. The branches operate a liaison officer support scheme. CFAI national office staff provide direct support to people in acute need and refer individuals or families in crisis to the counsellor in St. Vincent's Hospital, Elm Park, Dublin. CFAI part funds this counsellor to provide services to its adult members, most of whom attend the hospital as outpatients.

### *Financial support*

CFAI operates a social/distress fund through local branches and through the national office.

### *CFAI plans for support services*

CFAI organises a bereavement group on an informal basis in the Dublin area, with a view to developing this service in the long-term.

## **RECREATION SERVICES**

CFAI has a CF adult group with its own administrative structure. This group arranges regular outings, holidays and other social events for members throughout the country. CFAI assists in funding these opportunities. About 30 people are involved in these activities, with no waiting list. Young people identify themselves by joining the adult group.

## **VOCATIONAL SERVICES**

CFAI provides a CV preparation service. It also has a job club initiative, which is available, for example, on completion of each cyber campus course. In all, 15 people participate in the job club at present. This service is under review. CFAI is keen to assess the possibilities of teleworking for individuals with cystic fibrosis.

## **INDEPENDENCE SERVICES**

With improvements in medical and therapeutic intervention and care, people with cystic fibrosis have an increasing life expectancy. CFAI is actively involved in developing policies for services that will ensure the maximisation of independence and life opportunities for all young adults with cystic fibrosis.

As part of its policy development in this area, CFAI commissioned a study of barriers to and possibilities for independent living for people with cystic fibrosis. The research was part-funded by the Combat Poverty Agency and the Department of Education and Science. It identified vocational training, employment, housing and private transport as key issues for the promotion of independent living opportunities for people with cystic fibrosis. This research culminated in a report *Independent living for people with cystic fibrosis*, by Fiona Purcell (1998, CFAI, Dublin).

## **ADVOCACY SERVICES**

CFAI acts as an advocacy agency to ensure the best standards of service for every person with cystic fibrosis in this country. It is in regular contact with politicians, hospital authorities, health boards and government departments to ensure planning and delivery of services. CFAI has ongoing contact with the Department of Health and Children and will continue to seek funding from the Department of Education for its education service. It has organised direct action on issues and on individual cases. It plans to develop its advocacy role through its new paediatric policy.

It also provides an advocacy service to individuals by assisting them in obtaining mortgage insurance. It assists individuals in making claims for social welfare entitlements and for renovations to the home and supports these applications.

### *Links with other organisations*

CFAI has ongoing contact with the Small Firms Association and with the Irish Business and Employers' Confederation (IBEC). CFAI is a member of Disability Federation of Ireland (DFI) and is part of the Irish Donor Network.

# **DEBRA IRELAND**

## **DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION**

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### **INTRODUCING DEBRA IRELAND**

DEBRA Ireland was established in 1988 by parents of children with epidermolysis bullosa (EB). From the outset the aim of the organisation has been to support people with the condition and their families, to provide relevant information and support services, to assist the existing medical service response and to promote research into EB.

The main challenges facing the membership include the lack of resources to respond holistically to this rare condition. Lack of core funding and problems in fundraising means that continued employment of an EB specialist nurse is uncertain.

### **MEMBERSHIP AND STRUCTURE**

DEBRA Ireland has approximately 300 members, with no local or regional branch structure. It is a company limited by guarantee. Its charity number is CHY: 8703. The board consists of 6 members, with no age limits. It meets about 10 times per annum.

### **INCOME AND EXPENDITURE**

In 1998, DEBRA Ireland had a total income of £30,074. Of this, £23,979 (80% of total income) was obtained directly through fundraising and other charitable donations. The organisation uses the typical range of fundraising methods including corporate appeals, golf

### **EPIDERMOLYSIS BULLOSA**

Epidermolysis bullosa is a rare genetic skin condition which causes skin layers and internal body linings to separate and blister. Recent research has identified 22 different types of EB. It is never infectious or contagious.

About 1 in every 18,000 -20,000 babies is affected by EB, which, when severe, is obvious at birth. The person with EB has exceedingly delicate skin which is vulnerable to the slightest knock or rub which can result in painful sores and severe and persistent scarring. Even a mother's cuddle can lead to painful blistering of a child with EB. Scarred and tautened skin cause deformities and disabilities, particularly disfigurement of the hands. The condition also affects all of the mucous membranes, for example the eyes, inside of the mouth, throat, lungs and food pipe. In severe cases, EB is fatal in early childhood.

Existing treatments comprise various creams and protective dressings. The daily care of a person with EB can be lengthy, painful and distressing. The appropriate care of children with EB involves immense commitment from parents. Many people with this condition must undergo repeated surgery to remove scar tissue.

People with EB await a medical research breakthrough which will give an effective treatment for the condition. People with EB and their families sometimes find that the problem leads to isolation and stigmatisation.

classics and raffles. DEBRA Ireland received a total of £3,500 (12% of total income) from statutory sources (Eastern Health Board £2,000, Western Health Board £500, National Social Service Board £1,000). In addition, DEBRA Ireland participated in a CE scheme to the value of £3,000.

DEBRA Ireland also acts as a non-benefiting conduit for funds from a private trust fund (the Olivia Bannon Trust) to employ an EB nurse specialist in Our Lady's Hospital for Sick Children, Crumlin. DEBRA United Kingdom assists DEBRA Ireland by financing and facilitating the attendance of EB specialist nursing and health care professionals at the EB specialist clinic at Our Lady's Hospital for Sick Children, Crumlin. This service provided gratis is valued at about £5,000 per annum. No statutory financial assistance is provided for this quarterly visiting specialist expertise.

#### *Expenditure*

DEBRA Ireland spent £19,831 in 1998. This included almost £7,000 in wage costs, £854 on telephone charges and £2,940 on advertising costs. The excess of income over expenditure was brought forward to increase the staffing level of the organisation.

#### **STAFF**

DEBRA Ireland now employs a full-time manager with relevant qualifications. DEBRA Ireland had 1 CE worker until August 1999 and now employs this individual on a back-to-work scheme.

#### *CE scheme*

The organisation is appreciative of the efforts of individual CE workers, but finds the scheme as a whole is unsatisfactory from a number of perspectives. CE participants are generally poorly trained prior to job placement. FAS training is sporadic and poorly timed. Working hours are erratic and this can lead to problems in assigning tasks.

#### *Volunteers*

DEBRA Ireland is not in a position to operate a volunteer programme although it has contact with the Volunteer Resource Centre in the Carmichael Centre, where DEBRA is based. DEBRA Ireland benefits from the services of volunteers from the Volunteer Resource Centre to assist in the office as required. Board members undertake other voluntary duties. The organisation does not formally cost its volunteer input.

#### *Training and monitoring procedures*

DEBRA Ireland operates an informal induction and training programme for staff and CE workers and has no formal staff safety or monitoring procedures or stated written safety or complaints procedures and sees no immediate need for these in the light of the size and scope of the organisation. DEBRA Ireland would support the development of accredited training programmes for staff/CE workers. One area of possible development is in training in voluntary sector administrative assistance which could give employment mobility between organisations and an opportunity for career advancement.

### *Evaluation procedures*

DEBRA Ireland has never undertaken an independent or internal organisational or service user evaluation. The management is satisfied that it is in direct contact with members and understands and responds to members' expectations as far as its current resource base permits. The organisation is responsive to the development of formal monitoring and review procedures when resources permit.

### *Premises*

DEBRA Ireland has a desk in a shared office in the Carmichael Centre, in Dublin. This centre has disabled access and toilet facilities. DEBRA Ireland has a computer and the use of meeting rooms.

## **SERVICES**

### **INFORMATION SERVICES**

#### *Families with a child with EB*

DEBRA Ireland provides information to families with a child with EB and maintains contact with these families and individuals. DEBRA Ireland is introduced to families with a child with EB through the EB nurse specialist at Our Lady's Hospital for Sick Children in Crumlin, which is the main centre for the diagnosis and treatment of the condition.

#### *Information to medical and healthcare staff*

DEBRA Ireland sends information packs to hospital doctors, general practitioners, public health nurses and other relevant healthcare professionals as appropriate. DEBRA Ireland sends information about safe handling of newborns with EB to relevant staff in maternity hospitals as appropriate.

#### *Information to the public*

DEBRA Ireland has a web page which explains the nature of the condition, [www.debraireland.org](http://www.debraireland.org)

#### *Publications*

DEBRA Ireland produces an information leaflet, giving basic facts about the condition. It also supplies more detailed information, including a videotape, which it obtains through DEBRA UK. DEBRA Ireland produces a newsletter 3 times per year which is distributed to members and to interested individuals. DEBRA Ireland produces an annual report for members.

#### *Research*

DEBRA Ireland received a State grant of £30,000 which it gave to a research group at University of Dublin, Trinity College to examine genetic-based treatment for EB. DEBRA Ireland maintains information links with a European grouping of researchers which seeks to provide convergent research on the condition.



### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

DEBRA Ireland is a conduit for the funding of the EB nurse specialist at Our Lady's Hospital for Sick Children, Crumlin. Her role includes the coordination of all hospital medical assessments for individuals with EB. She also provides information, education and training to parents of children newly diagnosed with EB on daily dressings and skin care procedures. She provides support to children with EB, and their carers and to adults with EB, on a continuing basis, irrespective of locality. She provides an information service to general practitioners and community health nurses. The trust fund which finances the work of the EB specialist nurse is almost spent. DEBRA Ireland is eager to find a continuing source of funding for this post and to avoid losing the expertise of the employee.

Our Lady's Hospital for Sick Children, Crumlin holds a quarterly clinic for people with EB. This clinic is attended by the nurse specialist and by the manager of DEBRA Ireland. DEBRA Ireland benefits from the expertise of Great Ormonde Street Hospital London staff who attend the quarterly clinic and give their services free of charge.

### **SUPPORT SERVICES**

DEBRA Ireland does not operate a formal support service for its members. Any member may 'phone the organisation and will receive information and support as required. DEBRA Ireland is reliant on the services of the EB nurse specialist to provide ongoing support to families and individuals.

DEBRA Ireland lacks a branch structure and has found that the provision of an informal support network for members has been difficult, in part because of the amount of time spent in the care of children with EB. DEBRA Ireland would like to see local support for families but the organisation lacks human and financial resources in this regard.

#### *Respite services*

DEBRA Ireland rents holiday homes to assist needy families to take a break with their EB child.

#### *Financial support*

DEBRA Ireland has assisted individuals with EB through the provision of computers to aid them in schoolwork or at third level education. Most people with severe EB will have difficulties in writing.

### **ADVOCACY SERVICES**

DEBRA Ireland is the national representative group for people with EB and their families. As such, it campaigns for improvements in the health services available to this group. Its major focus at the moment is the retention of the EB nurse specialist post at Our Lady's Hospital for Sick Children, Crumlin. DEBRA Ireland maintains an ongoing commitment to the need for research into an effective treatment for EB. DEBRA Ireland will assist individual members in making claims for services to their health boards.

# DISABLED DRIVERS' ASSOCIATION OF IRELAND (DDAI)

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## DISABLED DRIVERS' ASSOCIATION OF IRELAND (DDAI)

### MISSION STATEMENT

The Disabled Drivers' Association takes care to present physical disability in the best possible light and strives to show that most physical disabilities can be overcome and individuals can go on to achieve their full potential with the benefit of support and training.

### INTRODUCING THE DISABLED DRIVERS' ASSOCIATION OF IRELAND

The Disabled Drivers' Association of Ireland (DDAI) was founded in 1970. It is an organisation of disabled people working for disabled people, promoting independence and equal opportunity through mobility. The association provides an extensive information, advice and support service to members. Through its subsidiary, Ability Enterprises, it provides education, training and employment opportunities for its members.

### MEMBERSHIP AND BOARD STRUCTURE

The DDAI has a national membership of approximately 3,600. Only people with disabilities may become full members. The association does not have a branch structure but operates offices in Cork and Ballindine. Services of the association are provided to all people with disabilities. The DDAI is a company limited by guarantee. Its charity number is CHY: 6384. All 8 board members (directors) are people with disabilities. Rotation consists of resignation of 2 members per year. The board holds 4 meetings per annum. There are no lower or upper age limits on board membership.

### INCOME AND EXPENDITURE

The DDAI receives training funds through the ESF. It obtains no central State or national lottery funding, but receives variable amounts each year from each of the health boards on a *per capita* basis for all individuals receiving disabled driver training. It depends on voluntary fundraising, membership subscriptions and donations. Its main fundraising annual events include

Bloomsweek in June, the sale of mistletoe at Christmas and the annual publication of a magazine which is sold to the general public.

#### **STAFF**

The DDAI employs 5 full-time staff members, 4 of whom are administrative and 1 driving instructor. In all, 40% of employees have physical disabilities. It is the policy of the DDAI to employ people with disabilities. All staff have necessary qualifications. The DDAI has no involvement with the CE programme. It has no formal volunteer programme, but some members assist with fundraising.

#### **PREMISES**

The DDAI has extensive office and training facilities at Ballindine, Co. Mayo. Ability Enterprises has fully equipped modern computer technology facilities. Residential accommodation is available on-site. The DDAI has 2 specially adapted cars for driver training.

## **SERVICES**

#### **INFORMATION SERVICES**

The DDAI operates a general information service for members on all disability issues and entitlements. It also offers specialist information and advice on all issues connected with disabled driving. For example, the DDAI informs members on how to obtain appropriate driving and parking documentation, on motor insurance, on the purchase or adaptation of motor vehicles, on claiming VAT, VRT and petrol refunds and on road tax exemption. The association supplies the necessary application forms for these entitlements and gives detailed written guidelines on how to complete them and puts members in contact with relevant statutory and other agencies as required.

#### *Publications*

The DDAI is in the process of developing a web page. The association promotes its work through its annual magazine called *Steering Wheel*. It also has a membership sticker and badge. It does not run media or public awareness campaigns, although it is often asked for its response to developments nationally. It does not produce an annual report or newsletter. It has a number of brochures and other information sheets about its range of services.

#### **EDUCATION SERVICES**

##### *Driver training*

People with disabilities who wish to learn to drive may do so at the Ballindine centre. The DDAI offers a residential 3-week intensive training course for any person with a physical disability. The person learns to drive a suitably adapted car and may go on to apply for the driving test. This service, including accommodation and meals, is provided free of charge to the learner driver. It is funded by a capitation fee from the regional health boards and DDAI resources.

## **SUPPORT SERVICES**

### *Disabled person's parking card*

The DDAI is accredited by the Department of the Environment to issue the disabled person's parking card.

### *Financial support*

The DDAI operates a number of benefits attached to membership. For example, members may avail of discounts on the purchase of new cars, on ferry passages and on package holidays. The DDAI operates a group scheme for VHI membership for its members. It also obtains motor insurance at competitive rates for disabled drivers. Membership of the DDAI gives free AA breakdown services to disabled drivers.

The DDAI has an educational bursary, established as a memorial to Martin and Ann Donoghue, the association's founders. This bursary is available to members who wish to pursue a course in higher education.

## **RECREATION SERVICES**

The DDAI has a holiday bungalow in Wexford and a house in Ballindine which are available to members and their families at a nominal rent.

## **VOCATIONAL/EMPLOYMENT SERVICES**

The DDAI's subsidiary, Ability Enterprises (founded in 1980), provides a range of training programmes, including work experience, in the areas of computer and office skills. All courses are funded through the European Social Fund (ESF) and have National Rehabilitation Board (NRB) approval. All give City and Guilds of London certification, or equivalent, on successful completion. Some of the courses are designed to enable people to obtain employment as teleworkers.

### *Centre-based training service*

Ability Enterprises runs a centre-based computer course at Ballindine. Among the courses on offer are business applications of the microcomputer, computer literacy and information technology, commercial reality training and introduction to data communications. At present, 7 students are receiving computer training from 2 tutors. Students may live at the Ballindine complex during their training. No fees are charged and students usually are paid an attendance allowance. All participants in the training programmes are given assistance and, if necessary, support to obtain and retain mainstream employment.

### *Distance learning service*

One of the courses run by Ability Enterprises is a distance learning programme, funded through the European Social Fund. Currently, 19 young people participate in a self-directed learning programme, with the support of a visiting tutor. This course lasts for 1 year, is accredited by the NRB and 5 tutors are attached to this course.

### *Transnational opportunities*

Ability Enterprises has also run training programmes, funded through the ESF, with a transnational component, giving young Irish people with disabilities work experience opportunities abroad.

The DDAI has cross-border links with a disability organisation in Belfast. Using Peace and Reconciliation funds the groups have developed a training project with an emphasis on social integration.

### **ADVOCACY SERVICES**

The DDAI is committed to promoting the independence of people with disabilities. It is an active advocate of disability rights. The DDAI has ongoing contact with politicians, health board officials and government departments. It makes pre-budget submissions to the Minister for Finance in relation to taxation issues affecting members and has been successful in extending tax concessions and benefits to specific groups of people with disabilities. The DDAI actively lobbies on various issues of concern to its membership. The DDAI believes that the political climate is more conducive to dialogue; it constantly strives to bring about change for the benefit of all who are disadvantaged by disability.

One of the main aims of the DDAI is to encourage members to be effective self-advocates. It assists people by informing them of their options and encourages them to take action on their own behalf.

# DISABLED PEOPLE OF CLARE (DPOC)

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## INTRODUCING

### DISABLED PEOPLE OF CLARE

Disabled People of Clare (DPOC) was founded in 1992 in response to the paucity of appropriate disability services in the Clare region. From the outset, DPOC has been a campaigning and lobbying group, taking direct action to preserve existing local disability facilities and to press for disability rights. The group has sought new ways to ensure its views are acknowledged and to put people with disabilities first, in all of its decisions. DPOC has direct links with Center for Independent Living (CIL) since 1994 and proclaims the CIL motto "*Nothing about us without us*".

Since its establishment, DPOC has grown to provide a range of services for people with disabilities in the Clare area. DPOC provides a personal assistant (PA) service to 14 leaders (people with physical disabilities). It provides accessible transport through a "vantastic" service. It gives office space to people with disabilities. It gives a voice to disabled people and provides them with training in community development and in computer skills with a view to employment.

### MEMBERSHIP AND BOARD STRUCTURE

DPOC has a membership of 110. Services are provided to nonmembers. DPOC is a company limited by guarantee. Its charity number is CHY: 11730. The board has 20 members, 15 of whom have disabilities and 5 are non-voting members. There is a membership rotation. The board meets monthly.

## DISABILITY RIGHTS

People with disabilities are entitled to the same rights as any other group. People with disabilities have the right to participate in the community on an equal footing with everyone else. To date, people with disabilities have been systematically marginalised by the community at large. The participation of people with disabilities has been watered down and segregated from the mainstream, by the provision of separate systems of education, training and employment. People with disabilities have been denied their legitimate social integration by deliberate policies of exclusion in areas of transport and public facility access. Some people with disabilities characterise able-bodied Ireland as operating an apartheid system for people with disabilities.

The disability movement argues from the perspective of fundamental rights. Disability activists seek a global and pan-European response to disabled people through the implementation of UN and EU principles. At national level, disabled people demand their rights to participate in their communities at different levels. They seek legislative assurance of those rights and expect government action to enforce those rights at every level of society.

## **INCOME AND EXPENDITURE**

All of DPOC's funding is project-based. The year 1998 was exceptional in that DPOC turned more than £420,000. Usually the group expends about £250,000. In 1998, DPOC received £80,000 from the EU through Directorate General (DG) V (now DG for Employment and Social Affairs) to fund a community arts project.

DPOC's main source of financial support comes from the FAS CE scheme which was valued at £190,000 in 1998 and which provided the bulk of funding for the PA service. DPOC also obtained a total of £40,000 from statutory sources other than FAS in 1998. This comprised grants from the Mid Western Health Board (£12,000 in 1998 as a set-up grant, £17,000 to part-fund the PA service, £5,000 in 1998 to assist in shortfalls in payment to the PA service, £6,000 from the national lottery), from the Department of Social, Community and Family Affairs (£22,000 to fund a group training project) and the Combat Poverty Agency (£2,500 for a research project). DPOC also received £2,500 from Disability Federation of Ireland (DFI) as part of a project to develop regional coordination of voluntary groups and agencies. It obtains about £2,000 per annum through charitable sources (mini-marathon participation), although on principle it does not fundraise.

## **STAFF**

The total number of paid staff in the organisation is 25, including 23 CE workers and a programme manager. In all, 2 full-time staff members are in administrative capacities and 3 have relevant/necessary qualifications/certification. DPOC also has 20 volunteers.

### *CE scheme*

The CE scheme is valuable in that it provides personal assistance for 14 leaders. The success rate of placement for CE workers in direct employment is 34%.

### *Training, monitoring and evaluation procedures*

DPOC operates induction programmes for staff, CE workers and volunteers. It is also involved in accredited training programmes in NCVA management, the NUI, Maynooth Diploma in Personal Assistance Training, the European Computer Driving Licence (ECDL) in computers, and CPR Red Cross certification. It also employs a wide variety of training with the CE workers. In October 1999, DPOC plans to commence a training programme for council members. DPOC finds it a constant challenge to source and fund trainers for members and staff and finds that existing financial support for training is inadequate. DPOC has stated written safety, complaints and reporting procedures. The organisation has never undertaken an independent or internal organisational or formal service user evaluation. The nature of interaction in the CIL is of constant criticism and review of activities and plans.

## **PREMISES**

DPOC headquarters are in Ennis, Co. Clare. Ennis is an Information Age town. DPOC, with the Central Remedial Clinic (CRC), Dublin, made a joint application to the Information Age fund and this led to the opening of new spacious and accessible premises for DPOC. The premises comprise a reception area, 4 offices and a spacious kitchen. There are drop-in and meeting facilities and free parking spaces. The group has 9 computers.

## SERVICES

### INFORMATION SERVICES

The group gives advice by 'phone and e-mail. DPOC has a website: [www.dopc.ennis.ie](http://www.dopc.ennis.ie)

#### *Publicity*

DPOC advertises its activities with a promotional leaflet and is regularly featured in the local newspaper. The group has been profiled in national magazines and on television. The arts programme of DPOC stages plays 3 or four times a year which bring an audience and a public profile. In 1996, the group hosted an international conference on PA services in Ennis with speakers from Europe which received both national and local media coverage. DPOC has journalistic contacts and has obtained media coverage for its activities and its agenda.

#### *Publications*

In 1999, DPOC produced a CD-rom on the topic of *Entitlements for People with Disabilities*. This was funded by a grant of £25,000 from the Department of Equality and Law Reform and has been distributed to the health board and other State bodies, semi-State and voluntary agencies in the region. It has produced a publication on issues in relation to personal assistants. DPOC does not produce a formal annual report. It has plans to produce a newsletter.

#### *Research*

DPOC has conducted a number of small research projects. In 1998, it examined the transport problems of people with disabilities in the Clare region, with the assistance of a grant from the Combat Poverty Agency. It also conducted preliminary research into the need for a PA service in Clare. This was funded by FAS with a sum of £1,000.

### RECREATION SERVICES

#### *Arts development*

DPOC has a commitment to the development of the arts for and with people with disabilities. It undertook a European-funded arts project that included 70 members in developing new ideas for staging the arts in Co. Clare in the context of community interaction. This project was worth £80,000 and DPOC was one of only two projects in Ireland funded under this initiative.

### VOCATIONAL SERVICES

DPOC provides free training in information technology and other relevant areas. At present, 8 people with disabilities are involved in computer-based training, assisted by a qualified trainer. The courses include ECDL, word processing and data base skills. This training is intended to lead to employment in telemarketing.

#### *Planned services*

Local multinational businesses have donated some computers to DPOC and the group intends to give these to people with disabilities in outlying areas to include them in activities of the group, to encourage local disability activism and to give educational, training and employment opportunities.



### **INDEPENDENCE SERVICES**

DPOC operates a personal assistant (PA) service which employs 23 CE workers to provide a service to 14 leaders. DPOC is eager to obtain permanent funding for this service. In all, 15 of the PAs are FAS CE workers, 8 are funded by the Mid Western Health Board for periods of 10-15 hours per week at an hourly rate of £6.00 per hour.

Only 2 of the leaders obtain a full PA service. All others receive a partial service, averaging about 15 hours per week. 6 of the leaders are in employment, directly as a result of having a PA. If additional PA hours were available, a further 4 leaders could be employed.

### **ADVOCACY SERVICES**

DPOC is active at all levels of advocacy on all issues that relate to people with disabilities. It has extensive contact with the local TD, health board officials and government departmental staff. As part of a national advocacy strategy DPOC produced a 10-point plan in association with the Centers for Independent Living and Disability Federation of Ireland (DFI), which advocated disability rights in the context of European and national social policy. Members of DPOC are self-advocates. The group promotes personal development skills that enable people with disabilities to control their own lives. People with disabilities are directed to mainstream courses on personal development.

#### *Direct action*

DPOC has taken direct action in the past and will continue to do so when it considers that such action is necessary.

#### *Links with other organisations*

DPOC is involved in the Limerick-based CIL and with the national Center for Independent Living (CIL) movement. It is a member of the Forum of People with Disabilities. It has representatives on the board of Disability Federation of Ireland (DFI) and on the Mid Western Health Board Committee on Physical and Sensory Disabilities.

## **FIGHTING BLINDNESS**

**(FORMERLY R.P. IRELAND -FIGHTING BLINDNESS)**

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off Mountjoy Square  
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Helpline: (01) 8034053  
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Fax: (01) 8559331

E-mail: [info@fightingblindness.ie](mailto:info@fightingblindness.ie)  
Website: [www//fightingblindness.ie](http://www//fightingblindness.ie)

Chief executive: Michael Griffith

### **INTRODUCING FIGHTING BLINDNESS**

Fighting Blindness was founded in 1983. Its aim is to raise funds for research and to provide support groups for people with degenerative eye diseases and their families. It now provides funds for 3 major research teams at University of Dublin Trinity College, the Mater Misericordiae Hospital in Dublin and the National University in Cork (UCC).

People with retinal degenerations await significant therapeutic developments. Fighting Blindness channels its activities into research to find these treatments. Fighting Blindness wishes to develop its counselling service and to strengthen its organisational structure but it faces a lack of public awareness about these conditions.

### **MEMBERSHIP AND BOARD STRUCTURE**

Fighting Blindness has a membership of about 500, with branches in Cork, Galway, Limerick and Tullamore. Services are provided to nonmembers. It is a company limited by guarantee. Its charity number is CHY: 6784. The board consists of 11 directors, with a rotation of one-third each year. The board holds 10-12 meetings per annum.

### **INCOME AND EXPENDITURE**

Fighting Blindness raised £135,492 in the year 1998/9. Its fundraising methods include concerts and street collections in Dublin and Cork. It also organises a "1000 choirs for sight" event. Fighting Blindness spent £133,660 in 1998/9. Total CE wage costs were £31,443 in 1998/9.

**STAFF**

Fighting Blindness has 3 full-time and 2 part-time employees. It participates in a CE scheme. It considers that the CE scheme has much to offer, when applicants are suitable. Fighting Blindness is not in a position to operate an accredited or in-house induction or training programme, other than those of FAS.

**PREMISES**

Fighting Blindness has a double office. The organisation cannot afford to provide disabled access. It has 4 networked computers. It has drop-in facilities during office hours and has access to meeting rooms.

## SERVICES

**INFORMATION SERVICES**

Fighting Blindness produces brochures, booklets and leaflets about degenerative blinding conditions. It produces an annual report and has a quarterly newsletter which is sent to members, including a version on audiotape. It holds meetings about degenerative blinding conditions. It is currently constructing a website. It conducts public awareness and media campaigns using press releases, radio and television interviews

*Research*

Fighting Blindness funds research into gene therapy at Dublin University, Trinity College. This project was initiated with the assistance of £100,000 from Fighting Blindness and now receives funding from the Wellcome Trust. In 1995, Fighting Blindness provided £10,000 to purchase essential equipment to establish a retinal transplantation research programme undertaken jointly by the Mater Misericordiae Hospital, Dublin and UCD. Also in 1995, Fighting Blindness commenced funding a study of apoptosis ( the technical term for programmed cell death) in UCC. This UCC project is the largest of its kind in Europe and now includes a small retinitis pigmentosa (RP) specialism.

**SUPPORT SERVICES**

Fighting Blindness provides a peer counselling network and holds group meetings in its branches. It operates two limited help lines.

**ADVOCACY SERVICES**

Fighting Blindness is the national representative organisation for people with retinal degenerative diseases and allied conditions. It seeks government support to fund research projects to find treatments.

# FOCUS IRELAND

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Website: [www.focusireland.ie](http://www.focusireland.ie)

Chief executive: Declan Jones

## INTRODUCING FOCUS IRELAND

Focus Ireland was founded in 1985 as a not-for-profit national organisation working with, and on behalf of, people out of home.

Focus Ireland aims to advance the rights of homeless people to live in a place they can call home, through the provision of quality services, research and advocacy.

In the past 10 years, Focus Ireland has undergone amalgamation and has expanded to include new sites and services in Limerick and Waterford. The organisation has four active divisions: housing, services, administration and finance, and research, development and education. Focus Ireland identifies the reduction of FAS-funded employment schemes as a significant problem for its operation. Funding is another core concern with ongoing shortfalls and lack of development resources.

## MEMBERSHIP AND BOARD STRUCTURE

Services are provided to nonmembers. The board of management comprises 9 members who hold approximately 10 meetings per annum.

## INCOME AND EXPENDITURE

Focus Ireland turns over approximately £4m per annum. Of this, about £3m is obtained through State sources with the remaining £1m coming through a wide spectrum of fundraising methods and events. Personnel related costs amount to £2.93m per annum.

## STAFF

Focus Ireland has 110 full-time staff. In addition, 108 people are employed through various EU and government programmes: 58 are CE workers, 30 are employed on the Jobs Initiative scheme and 20 are community service volunteers (CSV).

## HOMELESSNESS

Homelessness is the most extreme form of social isolation and exclusion and it is an enduring feature of Irish society. Official figures, from 1999, showed a national total of 5,234 homeless people at any one time, more than double the official figures from 1996. In 1987, 18,000 households were on local authority housing waiting lists. By 1999, this figure had increased to 45,578.

A strategy for the elimination of homelessness requires action to prevent homelessness, easily accessible emergency provision and short-term assistance, and appropriate long-term social housing provided by local authorities and housing associations.

### *CE scheme*

Focus Ireland describes the importance of the CE programme as enormous. The contribution of all employment programme workers is important, as is the philosophy of voluntarism, on which the organisation was founded. The success rate of placement for workers into mainstream employment has been very positive.

### *Training, monitoring and evaluation procedures*

A formal induction programme for volunteers is in place and an equivalent introduction for staff and CE workers is in preparation. All staff receive training on issues pertinent to their duties on an ongoing basis. Focus Ireland has a volunteer policy document which covers issues of safety, monitoring, reporting and complaints. Focus Ireland does not operate any accredited training programmes, but is examining the possibility of accreditation of the CSV scheme. Focus Ireland participates in an ongoing, independent, organisational evaluation and plans to commission an independent service user evaluation. In 1996, following amalgamation, it had an internal, organisational review.

### **PREMISES**

Focus Ireland has accommodation sites in Waterford, Limerick and Dublin. These sites provide more than 12 disabled access accommodation units. The organisation is computerised and has an internal database. Meeting rooms are limited in number, but redevelopment of sites will include increased meeting accommodation. In Eustace Street, Dublin, it has an open access coffee shop, used as a drop-in facility.

## **SERVICES**

### **INFORMATION SERVICES**

Focus Ireland provides a housing/accommodation information and advice service. In Dublin, it operates a crisis desk in the Eustace Street coffee shop where staff provide information and advice on social welfare entitlements and housing. The organisation has a website: [www.focusireland.ie](http://www.focusireland.ie)

### *Media and publicity*

Focus Ireland employs a public awareness manager, promotes its activities through the media and runs an annual *Focus on home* media campaign in the last whole week of November.

### *Publications*

It produces various fact sheets and has an extensive range of research publications. It has produced 3 information modules for use in secondary schools and is preparing one for use with 6<sup>th</sup> class primary school pupils. Staff give talks in schools in the greater Dublin area. An information module on homeless for students of nursing is in preparation.

### *Research*

Focus Ireland has undertaken and commissioned research and has published major reports on the situation of different homeless groups in Dublin and throughout the country. It now employs a researcher.

## **SUPPORT SERVICES**

Focus Ireland provides a wide range of personal and family support services which address the situation and needs of people at different stages of homelessness and reintegration into independent living. These services are provided in conjunction with housing services and are designed to enable people to gradually reintegrate into the life of the community. The organisation employs support workers/social workers to provide support services.

### *Crisis support services*

Focus Ireland provides crisis support services for people with emergency accommodation difficulties. These services include coffee shops, the crisis desk which provides information and advice, programmes for adults, outreach services, a nursery and creches.

Programmes for adults are in place. For example, some coffee shop customers participate in social, educational and personal development activities. In a centre-city drop-in centre, young people out of home can wash, do laundry and prepare food. The day centre has a programme of activities including arts and crafts, sports and leisure and discussion groups. Staff offer personal support and guidance to the young people.

The Focus Ireland outreach team goes out in the evenings and at night to make contact with young people who are out-of-home in Dublin city centre. The team offers support, practical assistance and advice and aims to establish a trusting relationship with people on the streets.

The Focus Ireland nursery is an all-day facility catering for the children of parents who are out of home. The children (7 months to 5 years) have a structured day and are given hot meals. The creches provide a drop-in child care facility for children up to 7 years of age of parents who are out of home and for families in crisis accommodation and in transitional housing.

### *Supports for individuals and families in transitional housing*

As part of the tenancy agreement between Focus Ireland and people in transitional or supportive housing, the person must attend a programme designed to help them come to terms with the reasons why they have become homeless. The course is structured, runs for a period of 4-9 months and includes individual counselling, group work and skills development.

### *Community settlement supports*

Focus Ireland operates a community settlement service to help people who have secured long-term accommodation to settle into their new homes. The service visits people at home, helps them to forge links with local support services, schools etc. and assists them with budgeting and money management.

## **RECREATION SERVICES**

Focus Ireland adult programmes provide leisure activities for customers. Residents of most of the sites have short holidays annually. Focus Ireland organises an annual Christmas party

## **VOCATIONAL SERVICES**

Focus Ireland uses the Jobs Initiative programme and CE schemes extensively. Focus Ireland opened a 7-day service for young people in November 1999, called the Loft, which includes a training element.

## **HOUSING SERVICES**

Focus Ireland provides a range of housing services from emergency accommodation through transitional housing to long-term accommodation. In addition to these housing services, it provides an extensive support service, designed to assist each person to come to terms with the reasons for their homelessness and to develop skills and resources to enable them to live successfully in the community.

### *Emergency assistance services*

Focus Ireland provides emergency accommodation for young people. This project, entitled *Off the streets*, is based in Dublin and caters for young people under the age of 18 years. Focus Ireland has plans further to develop its emergency accommodation. This has begun in Finglas, Dublin. The organisation also plans to build a foyer for young homeless people.

### *Transitional housing services*

Focus Ireland has 2 transitional housing projects, at Stanhope Green and at George's Hill, in Dublin. Focus Ireland intends shortly to open more transitional housing in Waterford. Transitional housing includes a structured short-term (less than 1 year) residential programme to support and assist people to live independently.

### *Housing services*

Focus Ireland assists people to settle back into the community by giving practical help, by providing housing or by assisting in obtaining local authority or private rented sector housing. It has housing sites in Limerick, Waterford and Dublin for approximately 200 individuals. It has plans to house another 250 people in 5 new housing developments.

## **ADVOCACY SERVICES**

Focus Ireland is a national non-governmental agency which seeks to influence national, regional and local policy in housing and related services. It has developed a policy framework through its research and promotes its perspective through ongoing lobbying and contact with national and regional political and administrative bodies. It uses the media to conduct advocacy campaigns. Focus Ireland's support workers act as advocates for individual customers.

# FRIEDREICH'S ATAXIA SOCIETY IRELAND

INCORPORATING OTHER HEREDITARY ATAXIAS

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Contact: Claire Creedon  
Joan Tierney

## INTRODUCING THE FRIEDREICH'S ATAXIA SOCIETY IRELAND

The society was founded in 1980 to provide information, advice and support to families and individuals with Friedreich's or other hereditary ataxias. It also acts as a pressure group to lobby government for improvements in services for people with these conditions and their families.

The society considers that the human rights of people with progressive disabilities are systematically ignored in Ireland. The society strongly supports campaigns for access and mobility. It also wishes to see improvements in home-based support and in respite services. It is concerned about the lack of secure, ongoing funding for organisations of its size and scope.

## MEMBERSHIP AND BOARD STRUCTURE

About 130 families with hereditary ataxias are members of the society. About 180 members of the association are physically disabled, with some families having 2 or more members with physical disability. The membership is national, with no branch structure, due to the small numbers of families in this situation nationally. Information is provided to nonmembers. Core support services are available to members.

## HEREDITARY ATAXIAS

Ataxia is the technical term for unsteadiness of body position or movement. The hereditary ataxias give rise to progressive problems of movement and coordination. All are rare and are genetically inherited, with both boys and girls potentially affected. Families in Ireland have 2, 3 and sometimes 4 children with the condition. Because of the rarity of the condition, families may be isolated and without real support.

Ataxia is usually not evident at birth, but becomes obvious in middle childhood. The parents and child face the diagnosis of a progressive condition. This can lead to significant emotional distress and family upheaval. Diagnosis of 1 child will mean that all other children in the family must be tested. Some families learn that other, usually younger children, will also develop the condition. All families learn that some of their members carry the gene and potentially may pass it to the next generation.

Most people with an inherited ataxia will eventually become unable to walk and will use a wheelchair. Upper limb movement is usually uncoordinated and so many routine activities of daily life are not possible. People with ataxia require substantial ongoing daily physical assistance to wash, dress and eat. In families with 2 or more children with the condition, this places immense strain on parents and other siblings.

Children and young people with ataxia typically require highly specialised educational facilities, including extensive use of computers to reach their academic and vocational potential.



The society has a written constitution. Its charity number is CHY: 7076. The board comprises up to 15 members, who are usually selected on the basis that they have something to offer the organisation and are available to attend meetings. Some board members are relatives. Others are medical specialists or business people. At present, 1 board member has a physical disability. There are formal rotation procedures and the board meets 12 times per year.

#### **INCOME AND EXPENDITURE**

The Friedreich's Ataxia Society Ireland obtains much of its funding through the Eastern Health Board (EHB). In 1998, it obtained a grant of £12,000 from the respite care fund, administered by the EHB. It also received £9,000 from the EHB to assist in the administration of the society. It receives no funding from any other health board source. It is reliant on fundraising for the additional approximate £20,000 required to cover annual expenditure. Fundraising methods include sponsorship in the marathon and corporate donation. In the past, the society has participated in a CE scheme, but this has now ceased. The society obtained a once-off grant of £10,000 from the People in Need trust for equipment purchase.

#### *Expenditure*

Staff wages are £160 per week. The annual respite holiday costs approximately £12,000. The 4 social events cost about £6,000 per annum.

#### **STAFF**

The Friedreich's Ataxia Society Ireland has 2 part-time administrative staff members, both of whom have relevant qualifications. The society can call on a variable number of volunteers, who assist with specific projects. The society does not cost its volunteer activity.

#### *CE scheme*

The Friedreich's Ataxia Society Ireland ceased involvement with the CE programme in the light of its dissatisfaction with the capacity and commitment of the trainees.

#### *Training, monitoring and evaluation procedures*

The Friedreich's Ataxia Society Ireland's size precludes in-house induction, training or volunteer programmes. Volunteers with direct physical contact with people with disabilities are under the supervision and guidance of volunteer, trained nurses. The society undertook a survey of members' preferences in the late '80s and developed its services on the basis of the results.

#### **PREMISES**

The Friedreich's Ataxia Society Ireland operates from a 1-room office in a private residence in a Dublin suburb. The home has disabled access and hygiene facilities. Many meetings of the society are held in the residence. The society has rented hotel facilities for large meetings. Respite holidays have been held in a variety of locations, from parish halls to disabled holiday centres.

## **SERVICES**

### **INFORMATION SERVICES**

The Friedreich's Ataxia Society Ireland provides an information service to anyone who contacts the society by 'phone, fax or e-mail. The society also runs occasional awareness weeks, in which it seeks publicity for the society and gives general information through the media. It held a national seminar on Friedreich's ataxia which was attended by medical, nursing and paramedical professionals.

### *Publications*

The society has a series of brochures and leaflets which outline the various ataxias and provide information on their management. Each of the ataxias is described in detail in separate brochures. The society has sent a special brochure about the conditions to every general practitioner in the country, to all hospitals and all neurologists. It produces a newsletter, usually once a year, but does not have an annual report.

### *Research*

The society has had involvement with a number of different research projects. It seeks to facilitate neurological researchers who wish to make contact with individuals and families affected by the hereditary ataxias.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

The Friedreich's Ataxia Society Ireland seeks to maintain close and cordial relations with medical specialists, including neurologists, psychiatrists and researchers. The society has 5 volunteer, trained nurses who assist each year at the annual respite holiday.

### **SUPPORT SERVICES**

The Friedreich's Ataxia Society Ireland seeks to support individuals and families in every way possible, given the society's limitations of size and resources.

### *Ongoing telephone support*

Members may 'phone the society during office hours to receive support and advice. Emergency calls are responded to outside of these times.

### *Social support*

The society runs 4 social events per year to which all members are invited. Members arriving in Dublin are met at the bus and train stations and overnight accommodation is provided if required. At these events, member families have the opportunity to meet each other and to talk in confidence to society officers, board members and medical advisors.

### *Visiting service*

The society officers have visited the homes of members and provided direct contact and support.

### *Respite services*

The Friedreich's Ataxia Society Ireland organises an annual week-long respite holiday for about 30 disabled people. Up to 33 volunteers assist during the week. The society also arranges respite breaks at other times during the year. The society will also attempt to find emergency residential respite placement for members in distress.

### *Financial support*

The society has assisted in paying for nursing care in and outside the home, including night turning. It has also provided finance to families and individuals for respite placement, physiotherapy, counselling and psychiatry, purchases of necessary equipment and transport. It helps families with advice and finance to modify and furnish ground floor accommodation to cater for the needs of a person or people with physical disabilities. The society operates a limited welfare fund for needy families.

### *Equipment purchase or loans*

The Friedreich's Ataxia Society Ireland has supplied 30 computers to young people with physical disabilities to enable them to access information and education. The society now intends to review progress in this area. The society has bought powered lift beds and powered wheelchairs through the aids and equipment budget of the Eastern Health Board.

## **HOUSING SERVICES**

The Friedreich's Ataxia Society Ireland provides the services of an architect, without charge, to any member family in the process of modifying the ground floor of their home for a disabled person.

## **ADVOCACY SERVICES**

The Friedreich's Ataxia Society Ireland is the national, non-governmental, representative body for families whose lives are affected by the hereditary ataxias. It seeks to engage in dialogue with the government and with the health boards (Eastern Health Board, Mid Western Health Board, Western Health Board and North Eastern Health Board to date) about the rights, entitlements and expectations of its members. It has ongoing contact with the Departments of Health and Children, Social, Community and Family Affairs, Equality and Law Reform and Finance.

It has presented detailed recommendations to the Minister for Finance on a wide range of disability concerns about social welfare payments, allowances, taxation and inheritance laws and made budget recommendations. It encourages all members to lobby for national and regional services. It supports individuals in their claims for entitlements.

### *Direct action*

It has encouraged its membership to run local access campaigns to highlight the lack of wheelchair access to State, health board, local government and other public offices.

**HEADWAY IRELAND**  
**THE NATIONAL HEAD INJURY ASSOCIATION**

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**This e-mail will change during 2000**

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Cork office: Unit 12  
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Director: Bernie Murphy

**HEAD INJURY**

Each year, approximately 800 people in Ireland sustain and survive a serious head injury. The typical age for head injury is between 25-30 years.

Males are twice as likely to sustain a head injury as females, mainly due to lifestyle risks. Young people who survive head injury can anticipate a normal lifespan. Their lives until the head injury have included relationships, employment, recreation, and often, parenthood. Each aspect of their lives may be sundered as a result of the head injury. Each of these people, young or old, will have long-term problems.

Acquired head injury gives rise to unique, individual, physical, intellectual, emotional and behavioural effects and changes in the individual.

**INTRODUCING HEADWAY IRELAND**

Headway Ireland was established in 1985 as a representative and support group. Its primary concern is to create understanding, support and public awareness of the multiplicity of needs of people with an acquired brain injury and their families. It campaigns with the message "saved lives must be lived".

Headway Ireland's service development has been rapid and, in part, shaped by the availability of funding opportunities. Its key achievement in the past 10 years has been the establishment of a specialist national service for its client group, including pre-vocational through to work retention programmes. It has developed a regional service structure and a growing network of local support groups.

Headway Ireland has a long-term aim to establish information, support and vocational services in each health board region. For the years 1999 -2001, Headway Ireland has submitting funding applications and proposals to all health boards for the establishment or continuation of head injury support groups, as a precursor to service development. Among its many targets are the establishment of a nationwide public awareness campaign and a national head injury week, the setting up of a national programme to inform and support teachers about head injury in the classroom, the expansion of its existing national helpline service and the development of a nationwide organisational structure by extending its remit into Northern Ireland. For Cork, the long-term development plans include the establishment of information and support services in the Cork office, the expansion of the existing vocational programmes and the creation of outreach services for clients who live in remote areas or who have no access to transport.

#### **MEMBERSHIP AND BOARD STRUCTURE**

Headway Ireland has a membership of more than 2,200 individuals and families. It has a network of branches in Dublin, Carlow/Kilkenny, Cork, Galway, Laois/Offaly, Mayo, Sligo and Waterford. It has priority plans for the development of support groups in Louth, Cavan, Meath and Limerick in 2000, in the context of a drive for a nationwide support structure. Headway Ireland also has support contacts in Northern Ireland.

Headway Ireland is a company limited by guarantee. Its charity number is CHY: 7417. Headway Ireland has a board of 12 voluntary directors, which meets monthly. The directors comprise a balance between family and professional members.

#### **INCOME AND EXPENDITURE**

Headway Ireland obtained £300,917 for all sources in 1998. This included £86,771 from ESF allocations in relation to its training and employment services, £107,000 from the Eastern Health Board, a once-off lottery grant through the Department of Health and Children of £50,000 in respect of the WAVE employment project and a grant of £5,000 from the Southern Health Board. Headway Ireland committed itself to a charitable fundraising strategy in 1997. By 1998, this programme had yet to show a profit for the organisation. Membership fees also constitute a small financial resource for the organisation.

#### *Expenditure*

The full cost of all Headway Ireland services for the year 1998 was £392,133. This included £304,193 on all vocational training programmes (including salary costs), £56,037 on information and support services and £31,903 on other administrative and service expenses. In 1998, Headway Ireland's direct staff salary and wages costs were £265,584.

## **STAFFING**

Headway Ireland employs 13 core full-time staff members, with a variable number of part-time and sessional staff. The staffing at national level consists of a director and event coordinator/officer manager. The organisation has 3 distinct services, Dublin (vocational), Dublin (information and support) and the Cork service. A coordinator is in charge of each of these services. The information and support service has a counselling psychologist who acts as the coordinator, a family support services officer, a psychologist and a part-time trainee information officer. The vocational training service has a coordinator, 2 vocational training officers and a part-time trainee vocational training officer. The Dublin services share 2 CE workers and 2 part-time administrative assistants. The Cork service has a coordinator, 2 vocational training officers, a trainee vocational and information officer and a CE worker. Headway Ireland employs a clinical neuropsychologist, a relationships and sex education tutor, a computer tutor, an art therapist, an anger management tutor and a creative writing tutor on part-time bases.

### *CE scheme*

In all, 4 CE workers are employed in Headway Ireland. Until late 1999, the CE workers at Headway Ireland were the sole source of administrative support within the organisation. Most CE participants have gone on to mainstream employment.

### *Volunteers*

Headway Ireland can call on approximately 40 volunteers, including its fundraising committee. Headway Ireland commenced a volunteer training programme in September 1999. This includes a selection process, training in head injury management and responses and a detailed understanding of the aims of the organisation.

### *Training, monitoring and evaluation procedures*

Headway Ireland has developed its own staff training programmes to enable the establishment of appropriate and innovative services for head injured individuals and their families. Headway Ireland has developed its own vocational and employment specialist staff training programme. It also trains its support staff, providing funding and paid leave for staff to attend professional courses. Headway Ireland trains its information staff to provide a professional service.

The board of directors of Headway Ireland instituted a comprehensive internal organisational review in 1998 which led to an overhaul of all existing services and the development of a strategic plan. Headway Ireland's vocational services have all been subjected to scrutiny by the National Rehabilitation Board (NRB). Headway Ireland has not undertaken an independent management or operational review. Headway Ireland has undertaken internal examination of its services and the views of service users.

## **PREMISES**

Headway Ireland's services are delivered at a variety of locations. All of Headway Ireland's premises are fully accessible. In Dublin, assessment, counselling services including telephone counselling, support groups and other support services, information services including a drop-in facility are available at Stewart Hall, in Parnell street, Dublin 1. These premises also provide facilities for some of the TOPS and Level I activities. The communications services, including fundraising, public relations, networking and lobbying are at Baggot Street. The Level I training

programme operates from Colaiste Ide, Finglas, Dublin 11. Headway Ireland has recently purchased a property at 101, Parnell Street which will be used for all Dublin staff, for the family resource centre and for the Dublin-based training programmes. In Cork, the office provides all main services.

## **SERVICES**

Headway Ireland is the sole provider of information, support and vocational services to individuals with acquired head injury and their families. Due to limited resources many services are available only in Dublin, with some of these services available also in Cork. Waiting lists exist for many of Headway Ireland's services, including the specific support services, particularly counselling, and the vocational services.

### **INFORMATION SERVICES**

#### *Information to members and families*

Since 1996, Headway Ireland has employed an information/research officer who responds to information requests received in the Dublin office and through the branch network. The Cork office provides a regional information service. Both services provide information by means of personal contact, telephone, post and through the branch networks.

#### *Drop-in information service*

Headway Ireland operates a drop-in information service at Parnell St, Dublin and at its Cork offices in Wilton.

#### *Public awareness*

Headway Ireland employs a half-time communications officer whose role is to raise public awareness about head injury, thereby increasing public and community support for people with head injury and their families. During 1999, Headway Ireland launched an ongoing public awareness campaign which focussed on print, TV, radio and internet media.

#### *Organisation of and attendance at seminars/conferences*

Headway Ireland's staff organise and attend relevant seminars and conferences and give presentations about the work and role of the organisation. Headway Ireland provides both medical and corporate presentations to a broad range of audiences. As part of its commitment to service development in Northern Ireland, Headway Ireland was involved in the organisation of a conference on brain injury rehabilitation in Belfast in November 1999.

#### *Publications*

Headway Ireland produces operational and organisational reports. Headway Ireland produces 2 newsletters, one circulated nationally and one focussed on the Cork region.

#### *Research*

Headway Ireland operates a small in-house research facility. Since February 1998, Headway Ireland's information officer, with external assistance, has designed and implemented a survey of head injured people in Ireland.

### Research library

Headway Ireland's research staff are currently amassing medical, occupational and psychological published research for a database for staff and other interested individuals. Headway Ireland also provides assistance to external researchers on head injury by provision of non-confidential information and setting up of contacts of members interested or willing to participate in research.

### *Data collection: statistics*

Headway Ireland provides accurate information and statistics to government and other funding bodies to obtain appropriate financial and other support for its activities. It is building a clients' profile database which will be an information resource to the organisation and other agencies.

### *Plans for information services*

Headway Ireland submitted a detailed proposal for its information and support service to the Eastern Health Board in December 1999.

## **EDUCATION SERVICES**

Headway Ireland provides placement and training services for professionals working in the area of head injury, with plans to develop this on a fee basis from April 2000.

### *Teacher training/in-service training in head injury identification*

Headway Ireland has presented a preliminary funding proposal to the Department of Education and Science to provide a teacher training/in-service training programme on the identification and management of head injury in the classroom. The organisation is also preparing a proposal for use of the internet as a means of interactive learning.

## **SUPPORT SERVICES**

### *Freephone helpline*

The Headway Ireland helpline 1890-200-278 was launched in October 1998. This is operated by existing Headway Ireland staff, with an initial screening and onward referral of calls.

### *Local support services*

Headway Ireland has a range of general personal support services which provide social and peer contacts for individuals with head injury and their families and close friends. In the main branches, general social support activities operate monthly for all families and friends of people with acquired head injuries. Headway Ireland has support contacts in Northern Ireland.

<b>CORE ATTENDANCE FIGURES FOR HEADWAY IRELAND SUPPORT GROUPS</b>	
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Dublin	50
Carlow/Kilkenny	25
Cork	35
Galway	45
Laois/Offaly	50
Mayo	10-15
Sligo	20
Waterford	30

### *Specialised peer support groups*

Headway Ireland provides a range of specialised peer support groups, in Dublin only, to assist people with specific needs to come to terms with their problems and to cope more effectively. These include the *social activities* group which aims to assist in social skills development for young men (aged 20- 30 years) who have sustained a serious head injury. This group caters for



a maximum number of 18 participants weekly. The *young men's* group aims to provide a group work setting for young head injured. The maximum number of participants is 8. The *couple's communication* group aims to provide couples, where one spouse has a head injury, with a forum to address issues relating to their relationship and to improve their communication skills in a supportive environment. Participant numbers are limited to 10. The *parenting* group aims to provide couples, where one has a head injury, the opportunity and assistance to revise and develop skills and mechanisms in coping and responding to their children. Participants on the course are limited to 8.

#### *Counselling service*

The counselling service (available in Dublin only) provides professional counselling support to individuals living with the after-effects of an acquired head injury who have serious problems of adjustment. The service offers individual counselling and psychotherapy, child and adolescent therapy, couple's counselling and family therapy and is staffed by 3 trained part-time counsellors. The existing counselling services assist 16 clients on a weekly basis. At present, 8 people are on the waiting list for this service.

#### *Plans for support services*

Headway Ireland submitted a detailed proposal for the development of its support services to the Eastern Health Board in December 1999. Headway Ireland made an application to the Southern Health Board for a counsellor and outreach worker. It also submitted plans to all health boards, except the Eastern and Southern Health Boards, to develop family support services. Headway Ireland will commence a service in the National Rehabilitation Hospital, Dun Laoghaire, Co. Dublin from mid-March 2000 and intends to open services in Beaumont Hospital, Dublin and in Cork University Hospital.

#### **RECREATIONAL SERVICES**

A children's support programme operated in 1998 only. The main activity here was a 2-week programme in the summer, with other seasonal parties for children. Headway Ireland has submitted an application to the Eastern Health Board to fund a staff member to research and develop a full-time recreational programme for children.

#### **VOCATIONAL SERVICES**

These were first established, in 1993, with the assistance of European Union (EU) Horizon funding and are the most developed of the existing services. Headway Ireland now operates 4 distinct vocational/employment services in limited geographical areas. All programmes work to capacity and have waiting lists.

#### *Reiteach vocational training programme (Dublin only)*

Reiteach (TOPS) is a personal development training programme for individuals with severe head injuries who exhibit major behavioural problems.

#### *Voice vocational training programme (Cork and Dublin)*

The *Voice* programme (Level 1) was created and established by Headway Ireland as a direct response to head injured individuals who are motivated to identify residual or possible skills to gain employment but who were unemployed prior to or as a result of their head injury. A similar Level 1 programme commenced in Dublin in October 1999.

#### *Jobtrail vocational/employment programme (Dublin only)*

Jobtrail is a programme which facilitates individuals with an acquired head injury to identify their strengths and weakness and to develop strategies to overcome problems they may have in everyday life as a precursor to return to employment, further education or further training. The employer-based training programme has a holistic approach to the individual and has both on-job and off-job components and provides family support.

#### *WAVE employment retention programme (Cork only)*

WAVE is an employment retention project, for individuals with head injury who were employed at the time of their injury. WAVE assists these individuals to retain their employment, using supported employment methods, with on-job and off-job components.

### **ADVOCACY SERVICES**

Headway Ireland is the national, representative organisation for individuals and families whose lives have been affected by head injury. It campaigns for a national policy on head injury with clear identification of the roles and responsibilities of all agencies involved. It seeks service provision within a continuum, to reflect the needs of head injured people. It lobbies the Departments of Health and Children, Social, Community and Family Affairs, Education and Science, Enterprise and Employment, Justice, Equality and Law Reform, Tourism, Sport and Recreation.

It seeks adequate funding to support current services and to develop appropriate community based integrated family support and outreach services. It produced a pre-budget submission in 1999. It campaigns for changes in the approach and methodology of pre-vocational and vocational training for brain-injured people. Headway Ireland represents individual clients in legal situations and acts in an advocacy role for individuals with other agencies.

#### *Links with other organisations*

Through its vocational services Headway Ireland maintains ongoing and comprehensive contact with the National Rehabilitation Board (NRB), which oversees the operation of some of the vocational programmes and which acts as a main source of referral. Headway Ireland is working with the NRB to achieve high standards in all of its vocational programmes. Headway Ireland is a member of the Association of Supported Employment. Its staff have researched supported employment in both the United States and in some of the European States. Headway Ireland has developed transnational links and networks with other agencies using supported employment methods.

# HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

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Development officer: Bernie Moran

## INTRODUCING THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND (HDAI)

The Huntington's Disease Association of Ireland (HDAI) was established in 1985. It provides a free and confidential consultation, information and individualised support service to people diagnosed with Huntington's disease (HD), their families and relevant and interested medical personnel. The association has extensive information links with international associations.

The aims of the HDAI are to provide specific information, advice, practical help and an ongoing and responsive contact to every member and family affected by the condition. It also seeks to avail of every opportunity to highlight the needs of members, *via* the media, politicians and others.

The past 10 years have been seminal for the association. In 1991, the President of Ireland, Mary Robinson became the patron of the association and this interest improved the profile of the group. Mary McAleese, President of Ireland is now the patron of the association.

## HUNTINGTON'S DISEASE

Huntington's disease is named after an American physician who described the symptoms in 1872. It is a genetic condition which causes certain groups of brain cells to deteriorate slowly and it affects movement, planning, memory, mood and insight. The condition becomes evident in adulthood, usually between the ages of 35 and 45. There is also a juvenile form and it sometimes presents in old age. The onset is highly variable in terms of the initial symptoms and the problem may not be diagnosed for some time.

Its genetic causation means that Huntington's disease is inherited and any child who has a parent with Huntington's disease has a 50% risk of inheriting the gene. As a result, when a person is diagnosed, all close family members may face uncertainty about their own futures and those of their children. They also face a decision on whether to take a predictive test to identify if they carry the gene.

Once symptoms appear, the condition is slowly progressive over a period of 15-20 years with the person becoming increasingly immobile, usually with involuntary movements, and with problems of concentration and speech formulation. Quite often the person with Huntington's disease is relatively unaware of the changes in their abilities and behaviour and this imposes additional strains on family members. At the later stages of the condition, eating and swallowing can be very difficult and the person is vulnerable to chest infections. At the end stage, the person requires intensive physical support.

At present, therapies to control the progress of the condition are limited. Some drug treatments can give relief from symptoms such as depression or extreme involuntary movements. Physiotherapy, occupational therapy, speech therapy and dental care all play an important part in maintaining the person's abilities and health as long as possible. One important finding has been that people with Huntington's disease fare better when they consume very high levels of calories daily (about 5,000 calories or twice the normal intake).

In 1993, the gene for Huntington's disease was discovered and from that a diagnostic test was developed. Some recent research gives hope for therapy. There is growing evidence that Huntington's disease is much more common than originally assumed. For the HDAI, this means that structural development of the organisation will require careful consideration.

#### **MEMBERSHIP AND BOARD STRUCTURE**

The HDAI has about 350 members. The association has no branch structure. The HDAI is a company limited by guarantee since 1998. Its charity number is CHY: 10130. The management committee is elected at the annual general meeting and consists of 8-10 members who meet monthly. The association has a staff subcommittee, a complaints subcommittee, an evaluation subcommittee and a research subcommittee. Some informal committee member training has been undertaken. Rotation has been limited to date, but conforms to the legal requirements. No age limit exists for management committee membership.

#### **INCOME AND EXPENDITURE**

The HDAI is funded primarily through the Department of Health and Children with lottery funding. This amounts to £40,000 per annum. The HDAI obtained £3,000 from the Respite Care Fund, through the Eastern Health Board. The association also received almost £1,000 from the Health Promotion Unit for publication of its information and has received money in the past from the People in Need trust. Voluntary fundraising is limited due to the absence of a branch structure and lack of public awareness of the issue. The HDAI is involved in fundraising through the marathon and seeks donations from companies. The HDAI has no annual fundraising day.

#### *Expenditure*

In 1998, the HDAI spent almost £50,000. Much of this was spent on the purchase of equipment and on development of a range of high quality publications. Salary costs were £16,800, with £9,064 spent on administration.

#### **STAFF**

The staffing of the HDAI is currently under review. From 1992, the association employed a full-time executive officer. This post continued to 1999. There is no full-time staff member at the moment, but the development officer deals with day-to-day duties. The association is now seeking to alter the role of staff and intends to fund a HD support nurse at the genetic clinic in Crumlin to inform, advise and support families at the time of diagnosis and throughout all stages of the condition.

#### *CE scheme*

The HDAI has taken a policy decision not to involve CE workers in the organisation to ensure privacy and confidentiality for its members. The HDAI is located in Carmichael Centre in Dublin and avails of the CE staff at the centre for routine administrative and clerical support.

### *Volunteers*

The HDAI has no volunteers other than its board members and the development officer.

### *Evaluation procedures*

The HDAI has not undertaken an independent review of its services or its organisation. The executive committee of the board seeks constantly to critique the association's activities. The HDAI has not examined service users' views. The association considers that it is in direct contact with service users already. The board makes decisions on behalf of members and reports to them at the Annual general meeting (AGM). Receipts and payments are checked by the committee each month and by the auditor before presentation to members at the AGM.

### **PREMISES**

HDAI has offices at the Carmichael Centre, Dublin.

## **SERVICES**

### **INFORMATION SERVICE**

When a person with a diagnosis of Huntington's disease, or one of their family members, first contacts the HDAI, the association provides introductory information and a one-to-one discussion about any issues of concern about the condition.

### *Freephone*

The HDAI operates a freephone number. It also has a mini-call number, which gives access to the development officer who will assist with information advice, support or provision of relevant local contacts.

### *HD ID cards*

The HDAI provides a Huntington's disease identity card to any member with the condition, free of charge.

### *Publications*

The HDAI has committed itself to providing publications of a high standard in terms of the information, layout, design and presentation. It contracted a professional design company to assist in this task and now has a number of clear information guides. It also produces a professionally designed, quarterly newsletter. The HDAI has a video on Huntington's disease which explains the condition. It also disseminates a range of 14 information leaflets in a resource pack format. The HDAI buys and distributes international publications, particularly from the Huntington Society of Canada. To date, the HDAI has not produced an annual report. An annual update on research and association development is sent to interested professionals. The HDAI gives talks to interested medical groups on request.

### *Research library*

The HDAI has a library of research and other resource materials on Huntington's disease. The development officer maintains regular internet contact with interest groups and collates medical and other developments in relation to the condition.

## **SUPPORT SERVICES**

Although a small organisation, the HDAI provides a 24-hour telephone accessed support service. The development officer will seek to provide whatever support is possible to any family in distress.

### *Support meetings/groups*

An informal support meeting is held monthly in Dublin and in Cork.

### *Respite services*

The HDAI is committed to assisting families with respite breaks. Families can apply for financial assistance for respite or holidays.

### *Financial support*

The HDAI operates a crisis fund and gives assistance where necessary for families to take respite breaks.

### *Purchase/loans of equipment*

The HDAI provides funds for the purchase of Kirton Huntington's disease chairs. These are specially designed to promote a relaxed and appropriate posture.

## **ADVOCACY SERVICES**

The HDAI focuses on advocacy activities. It has substantial contact with the Minister for Health and Children and departmental staff and the relevant minister in the Department of Equality and Law Reform.

The HDAI runs ongoing campaigns to further its aims. It seeks medical card provision for its members. People with Huntington's disease often find it difficult to obtain a medical card, yet the disease is a long-term illness. It campaigns for improved neurological care, for respite care and for counselling services to be available for any members in need. It seeks legislation to outlaw potential and actual discrimination against people at risk to Huntington's disease and to people with the disease, by insurance companies, mortgage lender and employers. It also sees its role as empowering individual members and families to negotiate services and supports for themselves locally.

### *Links with other organisations*

The HDAI has extensive international contacts and represents the views of families through the International Huntington Association and European Huntington Association networks. It is actively involved in the Inherited Diseases Organisation. It sees its membership of DFI as an important umbrella link.

# INDEPENDENT LIVING COMMUNITY SERVICES (ILCS)

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## INDEPENDENT LIVING MOVEMENT

The Independent Living movement focuses on the human and democratic rights of people with disabilities. The movement has existed since the 1960's and has been shaped by the demands and views of disabled people who wish to live their lives to the full within the community at large.

The core beliefs of the Independent Living movement include that all human life is of value and that everyone, regardless of disability, is capable of exerting choice. It also holds that people who are disabled by society's reaction to disability have the right to assert control over their own lives. The Independent Living movement uses PA services as a core mechanism for achieving personal independence for people with disabilities.

## INTRODUCING INDEPENDENT LIVING COMMUNITY SERVICES (ILCS)

ILCS was founded in 1996 to support and service the growth of the independent living movement in Ireland. Its role is to support the 26

Centers for Independent Living (CILs) throughout the country. It achieves this through training programmes and a general support of all CIL activities on request. ILCS identifies its main problems as lack of recognition of, and funding for, the independent living movement. It considers that it must respond to the broad range of abilities within the different CILs.

## MEMBERSHIP AND BOARD STRUCTURE

ILCS is not a membership-based organisation. The 26 CILs are affiliated to ILCS.

It is a company limited by guarantee. ILCS board of management consists of 7 members. The structure of the board has the Rehab Group with 4 board members and Center for Independent Living, Dublin has 3 members. The board meets 6 times a year.

## INCOME AND EXPENDITURE

ILCS obtains £100,000 in total each year, through Department of Health and Children subventions. It also receives a small amount of annual income from training fees. It does not seek to raise funds from other sources. The total wage costs per annum are £80,000.

## STAFF

ILCS has a total of 4 paid staff in the organisation: a general manger, an administrative assistant, a training officer and a development officer. In all, 3 staff members have relevant qualifications. ILCS does not operate a CE scheme for its own purposes. It has no volunteers. ILCS has written safety, complaints and reporting procedures. It has never undertaken any formal review of its operations.

## **PREMISES**

ILCS has offices in the Rehab Group head office in Sandymount, Dublin 4. This has full office administration facilities, canteen and parking, in addition to an office area. The building is fully accessible. ILCS has use of 3 computers and the full support of the information technology (IT) department. 5 meeting rooms are available, but there are no drop-in facilities.

## **SERVICES**

### **INFORMATION SERVICES**

#### *Publications*

ILCS activities are reported in the Rehab Group annual report. ILCS publishes a newsletter every three months called *The Independent*. ILCS has an information leaflet about its services. It provides information on request by telephone, e-mail and post. It supports the CILs nationwide with press releases and other media coverage. It provides information on the successful implementation of media and other publicity campaigns.

### **SUPPORT SERVICES**

ILCS is an administrative and resource support for the CILs. It gives administrative support in the preparation of proposals. ILCS also supports the establishment and development of an independent living network. This will lay down standards for the operation of CILs nationally.

### **VOCATIONAL/TRAINING SERVICES**

ILCS runs training programmes, certified through the National University of Ireland (NUI). These courses are for personal assistants (PAs) and for leaders. Induction courses and some home-based tuition occurs within these programmes. There are two centres for these courses: the PA course is in the adult education department at NUI, St. Patrick's College, Maynooth, the leader course is at the adult education department in University College Dublin (UCD). ILCS is examining proposals to run a course on disability awareness and equality trainers, with accreditation through NUI. ILCS proposes that a leader from each CIL in the country participate in this course and thereby develop expertise for use productively at local level.

### **INDEPENDENCE SERVICES**

ILCS provide a PA brokerage service for a number of health board users and on an individual basis. For example, the South Eastern Health Board and the Mid Western Health Board provide funds through ILCS to employ PAs for members of the CILs in their areas. ILCS channels these funds to the individual CILs, which, in turn, enable members to make arrangements to employ PAs of their own choice under their own control. ILCS arranges the PA and leader training and deals with PRSI and other employment bureaucracy.

### **ADVOCACY SERVICES**

ILCS presents pre-budget submissions and supports the CILs in their contact with government and other statutory agencies.



# INHERITED DISORDERS ORGANISATION (IDO)

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Hon. secretary: Alice O'Brien

## INTRODUCING THE

### INHERITED DISORDERS ORGANISATION

The Inherited Disorders Organisation (IDO) was founded in 1984 as an umbrella organisation. Its aims to raise awareness about the needs of individuals and families affected by such disorders. It campaigns for the provision of genetic counselling services and has been consulted by the Department of Health and Children in relation to the development of clinical genetic services in Ireland.

Since its establishment it has reflected the views of member organisations on issues of common concern and has presented a unified perspective on genetic issues. It liaises with international groups on genetic information. It collects, disseminates and exchanges information and seeks to collaborate with medical, research and statutory bodies.

The IDO continues to support the development of the national centre for medical genetics at Our Lady's Hospital for Sick Children, Crumlin, Dublin 12 and liaises closely with its 2 consultant clinical geneticists. The centre now provides clinics in Dublin, Cork and Galway and has 5 staff members trained in genetic counselling.

## MEMBERSHIP AND BOARD STRUCTURE

The IDO has 23 affiliated organisations, each representing groups of people with genetic conditions and their families. It is a company limited by guarantee. The IDO is managed by elected representatives from member organisations. This committee meets monthly and there is also an annual general meeting.

## INHERITED DISORDERS

Approximately 5% of people in Ireland live with an inherited disability. Their family members may develop the condition and/or may carry the gene and pass the condition to their children. Examples of genetic conditions include haemophilia, Friedreich's ataxia, neurofibromatosis and muscular dystrophy.

Recent years have seen enormous strides in the identification of the genetic causes of inherited disorders. Research into suitable gene and other forms of therapy are seen as potential breakthroughs for many individuals and families.

Ireland has been slow to develop genetic counselling and testing services. Even to the present day, many families with inherited conditions do not obtain an adequate genetic service.

The IDO points to the recommendations of the report of the Committee to Examine Medical Genetic Services in Ireland (the Tierney report). This report recommended the establishment of a user's forum which would comprise representatives of patients, e.g. the IDO, hospital authorities, research institutions, general practitioners, medical consultants and other users of the medical genetics services. This forum has not yet been established.

**INCOME AND EXPENDITURE**

The IDO has a small income from membership subscriptions and has received 2 grants, £2,000 from the People in Need trust in 1997 and £2,500 from national lottery funds through the Department of Health and Children in 1998.

**STAFF**

The IDO has no paid staff and does not participate in the CE scheme.

**PREMISES**

The IDO has a postal address at Carmichael Centre. It uses the facilities of member organisations for meetings and administration.

**SERVICES****INFORMATION SERVICES**

The IDO organises seminars and talks on issues of relevance to its members. It disseminates information about international and national developments to the constituent organisations. IDO members attend meetings on genetic issues at home and abroad and report back to members on developments.

**ADVOCACY SERVICES**

The IDO acts as an umbrella advocacy group for national organisations representing people with genetic and inherited conditions and their families. It seeks improved genetic counselling and screening services nationally.

# **IRISH ASSOCIATION OF THE SOVEREIGN ORDER OF MALTA**

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CEO: Comdt. Frank Hearn

## **INTRODUCING THE IRISH ASSOCIATION OF THE SOVEREIGN ORDER OF MALTA**

The Sovereign Order of Malta (the Order of Malta), a Roman Catholic organisation, has a long history. The order was founded in Jerusalem in the 11<sup>th</sup> century and has an unbroken history stretching 900 years. The Irish branch was established at Kilmainham Priory in 1174. For many centuries it remained dormant, following its suppression during the Reformation. It was revived in 1934. Today, the Order of Malta maintains its priorities, developed through the centuries, of care for the sick and the poor, in whatever practical ways are possible. The chief charity of the Irish Association of the Sovereign Order of Malta is its Ambulance Corps which involves 4,000 volunteer members organised in 86 areas throughout the entire island of Ireland. This group is well known for its first aid services. The Ambulance Corps is non-denominational and has grown considerably in the past 10 years.

## **MEMBERSHIP AND BOARD STRUCTURE**

The Ambulance Corps has more than 4,000 members in 86 branches throughout the entire island of Ireland. The Ambulance Corps branches are termed units and each unit is internally accountable for its own financing and service provision. Membership of a unit is open to all.

The Order of Malta is a company limited by guarantee. Its charity number is 4538. The Order of Malta has a military hierarchical structure. As part of this structure, the order has a council, to which members of the order are elected for a period of three years. The council of the Order of Malta is responsible for the Ambulance Corps through a director nominated by the order.

## **INCOME AND EXPENDITURE**

The Ambulance Corps obtains no European Union funds. On average, the Ambulance Corps might receive £50,000 annually from all potential Irish State sources. This could include grants of up to £5,000 from one or more health boards. It receives variable sums some years from national lottery funds distributed through the Department of Health and Children. All of these grants from the State are specifically earmarked for Ambulance Corps projects including purchase and equipping of ambulances. The central organisation undertakes no fundraising in its own right, but seeks assistance for individual units from both the State and from organisations such as People in Need.

Each of the 86 units of the Ambulance Corps is financially discrete and fundraises for its own purposes in its own locality. Each of the units submits audited accounts to the central office annually. On average, the annual total income of all units would come to approximately £300,000.

The 86 units of the Ambulance Corps spend about £250,000 in total, annually, on purchasing, equipping and servicing of ambulances and the provision of services in their locality. Most branches attempt to keep small amounts in reserve to fund new purchases.

#### **STAFF**

In total, 6 staff members work for both the Order of Malta and the Ambulance Corps at the Dublin office. These are the chief executive, an administrative officer, a stores officer, a youth officer, an accountant/bookkeeper and an office clerk. The Order of Malta has had a long involvement with the FAS CE programme, usually having 1 CE worker at any time. This participation has been beneficial generally and many of the CE workers have gone on to mainstream permanent employment.

#### *Volunteers*

The Ambulance Corps has more than 4,000 volunteers. About 2,000 of these people are adults. The other 2,000 are cadets. Cadets, male and female, are recruited between the ages of 10 -16 years. Cadets are trained to become senior volunteers, through a defined procedure, with the ongoing assistance of the youth officer, voluntary cadet leaders and officers. Recruitment of volunteers poses few problems for the organisation. Some people are recruited through the first aid courses, run by the corps throughout the country. There is also a strong family tradition of Ambulance Corps' membership and family members often encourage friends to join. The Ambulance Corps is keenly aware of safety concerns in relation to physical contact of volunteers and members of the public. It has safety, monitoring and reporting policies. Safety standards in each of the units are ensured by a trained cadet officer and by trained cadet leaders. As yet, the Ambulance Corps has not undertaken an internal or external organisational review but is examining this possibility.

#### **PREMISES**

The Order of Malta operates from offices in a large converted home in Dublin 4. Part of the building is wheelchair accessible. There are offices, a meeting room, a large hall and kitchens.

## **SERVICES**

#### **INFORMATION SERVICES**

The Ambulance Corps has a first aid manual published in conjunction with the Red Cross. Neither the Order of Malta nor the Ambulance Corps publishes an annual report, although internal reporting documents are prepared.

### **EDUCATION SERVICES**

The 86 units of the Ambulance Corps run first aid courses in their localities. They will also run courses for the commercial and business sectors on a fee basis. All of these courses are run to international standards and are accredited and certified.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

The Ambulance Corps provides first aid assistance at public events such as concerts, theatres and sporting fixtures. If the event is commercial, the Ambulance Corps will expect a donation from the organisers of the event. If the event is free of charge, the Ambulance Corps provides its services free of charge also.

### **SUPPORT SERVICES**

The Ambulance Corps provides a diverse range of support services, with each of the units providing services to suit the local area. Among the more frequent services are:

#### *Transport service*

The Ambulance Corps provides transport for elderly and disabled people to go shopping, to avail of social and recreational facilities or to attend church services or to travel home for weekends from long-stay institutions etc.

#### *Other support services*

Some units of the Ambulance Corps undertake home visits, particularly to elderly people. Some provide hot meals, day care centres, respite breaks, clubs for the elderly and day outings. Some units provide bathing facilities for frail and disabled people. The Order of Malta provides a meal service for the elderly, the St. John 's Club luncheon service, at its premises in Dublin 4.

### **RECREATION SERVICES**

The Ambulance Corps runs an annual holiday for young people with disabilities. This is held in Fermanagh. The corps is also involved in an international camp for young people with disabilities which is held in a different country each year. For the year 2000, the camp will be held at Stewart's Hospital in Palmerstown, Co. Dublin.

### **INDEPENDENCE SERVICES**

One of the aims of the transport service of the Ambulance Corps is to increase the personal independence of people with disabilities and elderly people.

### **OTHER SERVICES**

Neither the Order of Malta nor its Ambulance Corps provides housing or advocacy services. The Order of Malta Enterprises in Drogheda provides a vocational, training and employment service for people with disabilities (see separate entry).

# **IRISH ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS (IASBH)**

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**INTRODUCING IRISH ASSOCIATION OF SPINA BIFIDA AND HYDROCEPHALUS**  
The Irish Association of Spina Bifida and Hydrocephalus (IASBH) was founded in 1968 to provide information, support and services to individuals and families whose lives are affected by these conditions. The IASBH campaigns for official recognition of spina bifida and/or hydrocephalus as necessitating special consideration and high priority in the provision of services nationally. In the past number of years, the age profile of the membership of IASBH has

changed, from that of parent and child-focussed, to one in which adult members constitute two-thirds of the membership. This has led to a development of the philosophy of the organisation to include a growing emphasis on disability as a social, rather than a medical, issue with a consequent recognition of the civil and human rights of people with disabilities to participate as equals within society. There is a growing sense among members that fundraising for essential services is inappropriate and that these should be provided through the State as of right.

The association points to inadequate provision of, and long delays in obtaining, aids and appliances, including incontinence wear, footwear and wheelchairs throughout the health board system. Some branches wholly fund and supply additional incontinence wear to members. The national office administration is underfunded and is increasingly unable to respond to the extensive requests for information made by government agencies. Branches point to problems of transport and employment and criticise the absence of counselling services nationally.

## **SPINA BIFIDA AND HYDROCEPHALUS**

Spina bifida is a condition where the spinal cord (neural tube) of a foetus does not grow fully in the womb. The child born with this condition usually has to have surgery immediately after birth. The long-term effects can include weakness and paralysis of the lower limbs and problems with bladder and bowel control.

About 1 baby in every 600 births has spina bifida. The condition is probably caused by a combination of genetic and other factors. Research has proved conclusively that folic acid taken in early pregnancy reduces the risk of spina bifida by up to 73%.

The majority of children with spina bifida also have hydrocephalus. This is a blockage in the free flow of fluids around the brain. Sometimes it is necessary to surgically insert a valve into the head to overcome this blockage and to drain away excess fluid.

In the past decades, considerable advances have been made in the treatment and management of spina bifida and most individuals with the condition now play an active role in society. At the same time, research has also demonstrated some relatively unrecognised late effects of the conditions which may require intervention. These include Arnold Chiari malformation or the onset of hydrocephalus in adults with spina bifida only.

## **MEMBERSHIP AND BOARD STRUCTURE**

The IASBH has an active membership of approximately 1,000 families nationally. The association has 10 regional branches (Cavan/Monaghan, Dublin, Kildare, Kilkenny/Carlow, Louth/Meath, Roscommon/Mayo/ Leitrim, Waterford/south Tipperary, Westmeath/Longford, Wexford and Wicklow). Non-affiliated branches are also in contact with the association. Some individual members live in areas not covered by branches and are given services of the association.

The IASBH is a company limited by guarantee. Its charity number is CHY: 5833. The IASBH has a national executive committee, which comprises, at most, 35 members, drawn from the regional branches. The national executive committee meets 6 times annually. Rotation is voluntary. The national executive committee has made efforts to include young representatives (aged 16 years minimum). There is no upper age limit on national executive committee membership.

## **INCOME AND EXPENDITURE**

The IASBH requires that each of its branches submits audited accounts annually. Including the returns from all branches, it spent approximately £300,000 in 1999. About 70% of this sum is obtained through charitable fundraising undertaken by the branches. All branches fundraise through the local media. The national executive committee obtains no core funding from the State. The national resource office does not seek charitably sourced funds and obtains its income mainly through branch contributions.

Most statutory funding to the national organisation and to the branches is project-based. For example, in 1998, its independence training and respite services obtained £24,424 from health board sources, £30,000 in lottery funds, through the Department of Health and Children, and £10,000 from the Irish Youth Foundation. The IASBH received £78,000 in 1997, and £19,000 in 1998, from the Department of Health and Children for equipment, aids and appliances through the grant funding scheme. The Dublin branch of IASBH obtains a core grant from the Eastern Health Board of £64,000 to assist in operating its family resource centre. The Eastern Health Board also provided £5,000 to the Dublin branch in 1998 for respite services. The IASBH has obtained £2,000 from the North Western Health Board towards core funding for the national resource centre for 2000.

### *Expenditure*

The summer independence project cost £85,000 in 1998. Aids and appliances cost £79,360 in that year. The annual general meeting and seminars and a self-esteem conference for youth cost £15,181. For 1998, the total general and nonspecific expenditure, including salaries and PRSI, office administrative costs, travel, insurance and depreciation came to £53,741. The IASBH donates £2,000 per annum to Our Lady's Hospital for Sick Children, Crumlin for the employment of a specialist nurse. The IASBH estimates that it requires a minimum additional £35,000 per annum to maintain existing national services and has been operating in deficit for a number of years. A number of the branches also operate in deficit.

## **STAFF**

The national resource office has 1 full time administrator. The national office also assists in employing a liaison nurse at Our Lady's Hospital for Sick Children, Crumlin. The national office is responsible for the employment of nurses, occupational therapists, physiotherapists and helpers during the independence training summer project and respite programme.

### *Branch staff and volunteers*

The Dublin branch has a full-time secretary. It also employs an occupational therapist, an occupational therapy aide and a part-time driver in its day activity centre. The Dublin branch shares a family support worker with Muscular Dystrophy Ireland (MDI). Cavan/Monaghan branch employs teachers for home tuition and computer learning and a sessional physiotherapist. The Wexford branch employs a physiotherapist on a sessional basis. The Wicklow branch employs an occupational therapist and counsellor on a sessional basis. The other branches may employ occupational therapists, physiotherapists, teachers and nurses for their summer projects or for occasional periods. IASBH branches can call on about 60 volunteers nationally for a variety of support and fundraising tasks. The association has a voluntary youth officer whose role is developmental and wide-ranging. It includes involvement in the annual summer project, group work with young adults to develop their disability rights perspective, assistance with funding proposals for independence and personal development projects.

### *CE scheme*

The IASBH is investigating the possibilities afforded by the CE and other employment programmes.

### *Training, monitoring and evaluation procedures*

Most of the service provision staff of IASBH are trained professionals and are expected to conform to the safety and training norms of their respective professional bodies. The national executive committee is currently preparing codes of practice for volunteers. It has recently completed a health and safety statement. The Dublin branch adult activity centre was evaluated independently by the Eastern Health Board (EHB) in 1999, in association with its Section 65 funding.

## **PREMISES**

The national resource office owns premises in Clondalkin, west Dublin, adjacent to the grounds of Scoil Mochua. The office consists of 5 rooms and is fully accessible and has limited meeting facilities. The office has 2 computers. The building currently houses an independent footwear company specialising in the provision of footwear and calipers for people with disabilities. The Dublin branch owns a computer, but no other branch has computer facilities other than in personal ownership. In all, 3 of the branches (Louth/Meath, Wexford, Wicklow) own mobile homes for use in the summer.

### *Transport*

The national resource office owns a bus. The Dublin branch operates 2 buses for the resource centre and for outings.



## SERVICES

### INFORMATION SERVICES

#### *General information service*

The IASBH national resource office provides a telephone and postal information service to members, teachers, health care professionals and the general public. It promotes awareness of spina bifida and related conditions through seminars for members, parents, teachers and medical personnel and assists these groups to obtain additional information as necessary. It provides an information service to teachers in special and mainstream schools. It also provides information packs to secondary school students. It provides videotapes about various aspects of the conditions on loan.

The association is actively involved with the Department of Health and Children in a long-term information campaign on the importance of folic acid during pregnancy. It maintains ongoing links with the relevant spina bifida organisations in Northern Ireland, the rest of the United Kingdom and other countries.

Most branches provide an information service to members and families, to teachers, students and healthcare professionals. A number of branches run local public awareness campaigns. The youth officer provides information to young people on a wide range of disability issues.

#### *Publications*

The national resource office has a range of publications about spina bifida and related conditions. It has sent information sheets on hydrocephalus to general practitioners (GPs). It has published *Ability* magazine 4 times a year. This is sent to members, medical and paramedical personnel, teachers and other interested groups. The office has recently begun to publish a quarterly newsletter. Currently, the IASBH does not produce an annual report.

Most branches, except Dublin, circulate copies of the Association of Spina Bifida and Hydrocephalus, UK magazine, *Link*, to their members. The Dublin branch produces a newsletter about 5 times a year. The Waterford/south Tipperary branch produces a newsletter at least once a year.

#### *Research*

The national resource office maintains links with the Health Research Board and Dublin University, Trinity College on medical programmes which examine the causes and prevention of spina bifida and other neural tube defects. It assists in providing individual contacts for research purposes and all branches participate in research studies. The IASBH is active in supporting research into latex allergy, which is a serious and growing problem for members. The IASBH has obtained £8,000 from the National Social Service Board (NSSB) to investigate the feasibility of use of a folder format to provide an information package for use by voluntary organisations who provide disability related services.

#### *Planned information services*

The IASBH would like to develop a drop-in information centre at its Clondalkin headquarters and is in the process of setting up a website.

## **EDUCATION SERVICES**

### *School liaison service*

IASBH branch officials throughout the country, and the occupational therapist based in the day activity centre in Dublin, provide a school liaison service to inform teachers with a child with spina bifida and/or hydrocephalus in their class about any aspect of care or need of that child. This includes information on epilepsy and on nonverbal learning disabilities.

### *Home-based education services*

Waterford/south Tipperary branch provides home tuition for 3/4 students each year taking State examinations or who have enforced long absences from school or who require additional tuition. Cavan/Monaghan and Waterford and Wicklow branches also provide a similar service when requested.

## **MEDICAL/NURSING AND THERAPEUTIC SERVICES**

### *Liaison nurse service*

The national resource office part-funds a liaison nurse at Our Lady's Hospital for Sick Children, Crumlin. Her role includes the coordination of all hospital medical assessments for individuals attending the specialist clinics. She provides information, education and training to parents.

### *Physiotherapy and occupational therapy services*

Many branches provide a sessional, professional physiotherapy and/or occupational therapy service to members. The occupational therapist in the Dublin branch's family resource centre provides an early intervention therapy service whenever possible.

## **SUPPORT SERVICES**

### *Family support worker (Dublin branch only)*

In a pilot scheme, started in 1998, the IASBH shares a family support worker with Muscular Dystrophy Ireland (MDI) in the Dublin area. This qualified person visits families with newly diagnosed or young children with spina bifida and hydrocephalus and provides information, support, advice and coping strategies for parents. The family support worker has recently started to visit adults with the condition to provide support, identify problems and possible links with existing support services.

### *Support networks*

Most branches provide a telephone informal support network, especially for families with a child who is newly diagnosed. A number of branches operate a telephone hotline for families in crisis. The youth officer oversees a growing youth network within the association.

### *Parents support groups*

Most branches provide both formal and informal opportunities for parents to discuss issues of relevance to them.

### *Parent and baby groups*

The Dublin branch runs parent and baby groups.

### *Counselling services*

The IASBH points to the considerable unmet needs of members and families for counselling services. Peer parent counselling is available in some branches (Dublin, Louth/Meath). The IASBH occasionally provides funding to obtain bereavement counselling. IASBH members with disabilities have sometimes used the Irish Wheelchair Association's peer counselling service. This is a self-referral service and, as such, is not always utilised by people in need.

### *Respite services*

The national summer independence training project acts as a respite break for carers and also provides 5-day nonresidential placements for children and young people living in the Dublin, Wicklow and Kildare areas. The national resource office runs a respite care week every summer to provide a respite break for families and carers of people with profound physical and mental disability. Dublin, Kildare Waterford/south Tipperary, Wexford and Wicklow branches assist in respite provision.

### *Visiting services*

Dublin, Kildare, Waterford/south Tipperary branch officers or members occasionally make home visits to families.

### *Financial support*

Most branches provide financial assistance to needy families. Many branches provide assistance with driving lessons and motor insurance. Many branches give financial support to assist members to travel to hospitals, including accommodation costs and will consider other applications. In general, the funding ability of the branches is limited.

### *Equipment purchase or loan*

This is usually undertaken through the branches. Most branches have raised funds to purchase equipment. The Wicklow branch funds and supplies necessary, additional incontinence wear, which the local health board does not supply. The Wicklow branch also provides computers for use in and out of the home.

## **RECREATION SERVICES**

Most branches have some level of recreational support services ranging from Christmas parties to kids' or sports clubs and day outings. The youth officer is involved in the planning and organisation of holidays for young adult members.

## **VOCATIONAL SERVICES**

The IASBH provides work experience for a small number of members with disabilities in its national resource office. The Dublin branch provides a vocational element in its day activity centre, where some of the participants produce greetings cards.

## **INDEPENDENCE SERVICES**

The youth officer of the IASBH has a developmental role within the association to enable young people in the association to develop an independent living philosophy. The national resource office runs a national residential summer independence training project every year. This focuses

on life-skills and mobility training in the context of a relaxed environment. It includes members aged from 7 to 30 years of age. At the Annual general meeting (AGM), members may attend a personal development seminar. A small number of IASBH members with disabilities have a personal assistant (PA) service operated through the Irish Wheelchair Association (IWA).

#### **ADVOCACY SERVICES**

The IASBH is the national non-governmental representative body for individuals and families whose lives are affected by spina bifida and/or hydrocephalus. The national office has ongoing contact with government departments and health board administrations. It has an extensive campaigning agenda, derived from ongoing consultation with branches which ensures that members' views are represented to relevant central and regional State bodies, national commissions and committees.

The IASBH seeks representation on each of the health board co-ordinating committees for people with physical and sensory disabilities. It seeks adequate training for health board and other service personnel in disability awareness. It monitors problems experienced by members throughout the country and brings these to the attention of relevant government bodies. It campaigns for improved provision of carer, disability and domiciliary allowances and for improvements in the supply of incontinence wear and other aids and appliances, including wheelchairs. It seeks personal assistants (PAs) for school children. The IASBH advocates the provision of a family support worker service in each health board region.

The IASBH youth officer has a role in formulating policy at local and national organisational levels, and in making submissions to State bodies, e.g. the Equality Authority. The youth officer also gives assistance to young adult members wishing to make submissions to State and other agencies on a wide variety of issues.

The national resource office assists all branches in formulating service plans, funding applications etc. for submission to the relevant health boards and other bodies. The national office promotes self-advocacy and has held a number of self-awareness and capacity building sessions in Dublin. It supports students seeking suitable accommodation in the Dublin area.

A small number of branches actively promote self-advocacy. Some of the branches act as advocates on a range of issues including incontinence wear, school issues, planning permissions and renovation grants. The Cavan/Monaghan, Dublin, Wicklow and Wexford branches have ongoing contacts with local/regional and national politicians.

#### *Links with other organisations*

The association is an active member of Disability Federation of Ireland (DFI), the Neurological Alliance, Welfare of Children in Hospital, the Care Alliance, the International Federation for Spina Bifida and Hydrocephalus and the Irish Society for Quality in Healthcare.

# IRISH DEAF SOCIETY

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## INTRODUCING THE IRISH DEAF SOCIETY (IDS)

The Irish Deaf Society (IDS) was founded in 1981. It seeks to represent deaf people in Ireland. The IDS views deaf people as a linguistic minority with their own language, Irish Sign Language (ISL). In the past, it has obtained EU Horizon programme funding to train sign language/spoken English interpreters. The society acts as an advocate of deaf people's rights and has led a number of campaigns including one to increase subtitling of television programmes. The IDS has no core funding. This means that the society has not been able to develop its structures or its responses to member groups. The IDS seeks core State to enable it to fulfil its representative role and to employ key management staff.

## MEMBERSHIP AND BOARD STRUCTURE

The IDS is an umbrella organisation with 25 affiliated local deaf groups. It has a membership of 400 people. Most members are deaf. It is a company limited by guarantee. Its charity number is CHY: 8674. Its board of directors consists of 12, with a 5-member executive committee, elected at the Annual general meeting (AGM). All board members are deaf. Board membership rotates every 4 years. The board meets 10 times a year. The IDS is recognised by the World Federation of the Deaf and the European Union of the Deaf.

## INCOME AND EXPENDITURE

The IDS operates under considerable financial constraints and has no ongoing, core State funding for key personnel or organisational structures. In 1998, it obtained a grant of £9,000 from the Eastern Health Board. Its staff complement of 25 was funded almost entirely through a CE scheme. FAS also provided £11,867 of direct income to the IDS for administration costs. The society obtained almost £25,000 through fundraising and donations and £10,493 through its flag days. It received £14,151 from the European Commission, earmarked for a European project. It also received £4,281 from the Women's Education Initiative. It received £5,214 through Deaftronics, a sales outlet and £2,346 through its publications.

### *Expenditure*

In 1998, the IDS spent £93,961 and was almost £9,000 in deficit for the year. Its expenditure included £15,500 associated with the FAS CE scheme and £14,151 on its European Union project, £13,404 on additional wages, £9,865 on office maintenance, £5,755 on administration, £3,941 on the *Irish Deaf Journal*, £3,336 on mortgage interest, £2895 on travel expenses. It also spent sums on interpreter services (£2,166), congresses (£1,372), women's education (£1,361) and video projects (£668).

### **STAFF**

The IDS employs 25 staff members, all of whom are CE workers. They work as administrators, receptionists, librarian, secretarial support, technical staff, video project staff and publications staff. In the year 1999, the IDS employed 2 additional part-time staff at a cost to the organisation of £13,604.

### *CE scheme*

The IDS is wholly reliant on a CE scheme for its operations. As such, the scheme is beneficial to the organisation, but its lack of developmental potential makes it, ultimately, a limited and limiting contribution.

### **PREMISES**

The IDS operates from offices in Dublin 1. These consist of a reception room, computer room, board room, canteen, library, technical room and video project. The building is not wheelchair accessible.

## **SERVICES**

### **INFORMATION SERVICES**

The IDS provides an information service on deaf societal needs such as Irish Sign Language, deaf culture, heritage, the deaf community, deaf education and communication access.

### *Seminars, lectures, workshops*

The IDS organises public events which deal with deaf issues.

### *Library/publications*

The IDS has a library facility at its head office. This stocks books and periodicals on deaf issues (reference only). The society also produces a quarterly publication, the *Irish Deaf Journal*. The IDS publishes information videos on deaf-related issues.

### *Research*

The IDS has an involvement in research on the topics of cochlear implants, telecommunication advances, access in public places and the deaf school.

## **EDUCATION SERVICES**

The IDS provide literacy courses, on an ongoing basis 2/3 times a year.

### *Educational videos*

The IDS has a video project which produces quality educational videos to teach sign language. The society is currently working on producing children's educational programmes.

## **SUPPORT SERVICES**

Deaf people may be isolated in their communities. The IDS seeks to support deaf people and to provide them with opportunities to meet other deaf people and to participate in social activities.

### *Interpretation service*

The IDS used to provide sign language interpreters for deaf people at interviews, court cases and other assignments. This service is now provided by a new independent agency, ISL Link Agency, which is based in the National Rehabilitation Board offices, 25 Clyde Road, Ballsbridge, Dublin 4 Tel/minicom (01) 6080437, Fax: (01) 6685029.

### *Women's group*

The Irish deaf women's group meets fortnightly in the Deaf Club, 40 lower Drumcondra Road, Dublin, 9. The aims include personal development and assertiveness. The format for meetings includes talks and lectures on topics of women's health. The IDS wishes to develop a course for deaf women to become tutors in health education.

### *Mother and toddler group*

A mother and toddler group takes place during mornings. It includes many of the features of the women's group above.

### *Irish Deaf Youth Association*

The Irish Deaf Youth Association (IDYA) secretary is based in the IDS and the group uses the premises for meetings. They organise social events for young deaf people to reduce isolation and encourage mutual support among the young deaf.

### *Equipment purchase or loan*

Deaftronics is a commercial company, sourcing and selling a wide range of technical aids suitable for deaf people, e.g. alarm clocks, flashing lights and video caption readers. It provides a repair service for some of these aids. This company may be contacted through the IDS.

## **RECREATION SERVICES**

The IDS organises day outings and Christmas parties for children in the organisation.

## **VOCATIONAL SERVICES**

The IDS trained 10 interpreters and four sign language tutors in 1992-4. These projects were funded through the EU Horizon programme. The IDS campaigns for professional training for interpreters in Ireland.

### **ADVOCACY SERVICES**

The IDS seeks to represent the views and aspirations of deaf Irish people. It seeks the recognition of the civil and social rights of deaf people in Ireland. It campaigns on a number of core issues. These include alterations to the educational curriculum in deaf schools to teach Irish Sign Language as a first language and English as a second language, in line with recent international developments. It has led campaigns in other areas including health, training and employment. It seeks professional training of sign language interpreters. It advocates increased subtitling of programmes. In these contexts, it has lobbied central government departments.



## **IRISH GUIDE DOGS FOR THE BLIND**

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### **INTRODUCTION TO IRISH GUIDE DOGS FOR THE BLIND**

Irish Guide Dogs for the Blind was established in 1976. The aim of the association is to provide a residential mobility service for the blind, to the highest international standard, free of charge, to enable blind people to achieve their full independence and potential. The functional training centre opened in 1980 to train individuals to use a guide dog. In 1988, the service expanded to include training in the use of a long cane.

The association has problems in recruiting qualified trainers and instructors and wishes to upgrade its training facilities for new apprentices. Some of its recruitment and retention problems stem from its inability to compete with the pay scales of industry and business. Its high reliance on charitable fundraising is posing increasing strains on its capacity to maintain and develop a quality service.

### **MEMBERSHIP AND BOARD STRUCTURE**

The Irish Guide Dogs for the Blind has a national membership of about 200. It has 75 branches throughout Ireland which function to raise funds. Services are provided to nonmembers. The board of management comprises 14 members, with one-third of the board retire each year and may offer themselves for reelection. The board meets 6 times per year.

### **INCOME AND EXPENDITURE**

Irish Guide Dogs for the Blind turns over about £925,000 per annum. It receives £150,000 from State sources. It is reliant on fundraising for approximately £775,000 each year, equal to 84% of its annual budget. Fundraising is undertaken by the 75 branches through local events. The association spends £611,000 per annum on staff costs.

## **STAFF**

Irish Guide Dogs for the Blind has 28 paid staff, of whom 4 are administrative. In total, 14 staff members have necessary/relevant qualifications. It employs a veterinarian to oversee the health of its dogs and a number of dog trainers. The association does not participate in a CE scheme. About 750 - 1,000 volunteers assist the association, mainly through fundraising.

### *Training, monitoring and evaluation procedures*

Irish Guide Dogs for the Blind has an induction programme for staff to assist them in dealing with people who are blind or visually impaired. It operates accredited training programmes for staff allied to the City and Guilds qualifications. It occasionally runs other in-house training programmes. It sees value in developing additional accredited training programmes. The association undertook an independent organisational evaluation in 1985.

## **PREMISES**

Irish Guide Dogs for the Blind has residential, administrative and kennels facilities at its Cork location, with limited disabled access. The association has little reliance on computerisation, no drop-in facilities and limited space for meetings. A new dog complex was opened in 1999 and a new residential and administrative unit are planned for 2001.

## **SERVICES**

### **INDEPENDENCE SERVICES**

#### *Mobility training service*

Irish Guide Dogs for the Blind provides clients with a residential mobility training programme to use a guide dog or long cane. The association also provides the dog or the cane. Since 1980 300 guide dog units (ie owner and dog) have been trained and more than 120 long cane users have been trained since the introduction of this service in 1988.

# IRISH HAEMOPHILIA SOCIETY (IHS)

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**THE IRISH HAEMOPHILIA SOCIETY**  
The Irish Haemophilia Society (IHS) was founded in 1968 and for almost 20 years it remained a small support organisation with no paid staff. In the late 1980's, following on the infection of people with haemophilia with HIV and later with hepatitis C, through the administration of contaminated blood products (see box), the IHS began to employ staff to campaign for appropriate health and support services for its members and to seek compensation from the State for all of its members who had been affected.

The IHS sees its role as representing members and their families on all issues relating to haemophilia and its management, providing education and assistance for all people with haemophilia and other bleeding disorders, monitoring existing health services for people with haemophilia and campaigning for the best possible treatment.

## HAEMOPHILIA

Haemophilia is a rare inherited bleeding disorder. A person with haemophilia produces little or no natural blood clotting factor. Even a minor injury can cause bleeding which is not stopped naturally through blood clotting. The person continues to bleed painfully, often internally, into the soft tissues and the joints of the body. Prior to modern treatment advances, people with haemophilia sustained progressive damage to their joints, particularly in their legs.

The genetic cause of haemophilia is on the X chromosome. In simple terms, this means that only boys have haemophilia, girls in the family may carry the gene.

No cure exists for haemophilia. Treatment has made significant advances in the past two decades. Now, every child with haemophilia is given prophylactic (i.e. preventive) treatment. This treatment uses a product which is injected 3 times weekly. It raises the blood clotting factor level in the blood and protects against excessive bleeding and joint injury. If a person with haemophilia sustains an injury, this regular treatment may be insufficient to stop bleeding and immediate specialised medical intervention may be required.

The advances in the treatment of haemophilia mean that life expectancy is normal and the quality of life is acceptable. However, this success story is complicated by the fact that during the 1980's and 1990's the various developing treatments for haemophilia used substances which were extracted from human blood. Some of this blood was contaminated with HIV, which can lead to AIDS, and with hepatitis C, a highly destructive liver virus. Many Irish people with haemophilia were infected with HIV and/or hepatitis C. 45 people with haemophilia are living with HIV infection and 58 people with haemophilia have died of AIDS. In all, 210 Irish people with haemophilia have hepatitis C, including 10 children. Ten Irish people with haemophilia have died of hepatitis C. As a result, all treatments for people with haemophilia now rely on nonhuman sources and are manufactured to avoid any possible contamination.

The IHS identifies as its main gains in the past 10 years the success of the ongoing HIV compensation campaign including the establishment, in 1990, of the Haemophilia HIV Trust (HHT), a fund of £1m set up by the State for members who had contracted HIV. The IHS receives a grant to enable it to provide Hepatitis C services including counselling, weekend seminars and publications. The IHS has developed its own blood policy which sets out the standards of safety and assurance necessary for the production and use of blood products. The society has been instrumental in increasing public and health service awareness of rare bleeding disorders affecting women.

The main task in the future for the IHS is to ensure the establishment and operation of an inherited bleeding disorders treatment centre at St. James's Hospital, Dublin. This will ensure that people with haemophilia and other rare bleeding disorders can receive the best treatment in a specialist unit. The IHS wishes to achieve an equitable resolution of outstanding concerns in relation to HIV compensation. It also wishes to ensure that the children with haemophilia who contracted hepatitis C will be supported in the long-term.

Haemophilia is a rare condition. Other bleeding disorders are even rarer. One is von Willebrand's disease which affects women.

#### **MEMBERSHIP AND BOARD STRUCTURE**

The membership of the IHS is approximately 350. The IHS does not have a formal branch structure, although a support network exists in Cork. It is a company limited by guarantee. Its charity number is CHY: 9214. The executive committee of the IHS consists of 8 members. Rotation has been limited to date, although the society is about to alter this. There is no upper age limit to membership of the committee. All IHS services are available to anyone who has a bleeding disorder and to any of their family members.

#### **INCOME AND EXPENDITURE**

In 1998, the IHS obtained 274,734 in income. Much of this was provided by the State. A total of £96,000 was obtained from the Eastern Health Board under the Section 65 grant system and was for services for members with HIV. The sum of £57,000 was paid to the IHS for services to members with hepatitis C. Donations to the organisation amounted to £69,562 and fundraising activities brought in £11,813. Methods of fundraising are diverse and often involve an information element. Major fundraising is undertaken by staff, members and friends of the organisation. The IHS has obtained funds through mini-marathon participation, a national non-uniform day, grand draws and once-off events.

#### *Expenditure*

In 1998, the IHS spent £220,978. Of this, £89,709 was spent on staff wages and salaries. Much of the rest of the expenditure was on services to members affected by HIV and/or hepatitis C. The HHT pays for half of a part-time counsellor's salary, in the region of £3,000 per annum, in Cork Regional Hospital.

## **STAFF**

The IHS employs 6 paid staff, 3 of whom are administrative. All staff have relevant qualifications.

### *CE scheme*

The IHS has no involvement with the CE programme. This is a policy of the organisation and reflects the need for privacy and confidentiality of its members, particularly those with HIV or hepatitis C. Members of the IHS volunteer for various activities in the organisation, such as provision of emotional support or of overnight accommodation to other members, but no volunteer programme is in operation.

### *Training, monitoring and evaluation procedures*

Staff undertake appropriate training and updating of skills whenever necessary, external to the organisation. All new staff are given induction training. The IHS does not operate accredited training programmes and sees little value in them due to the small size of the organisation. Members and staff are well-known to each other and there is an implicit trust between them in relation to safety protocols, physical contact etc. The IHS is confident that its tight network ensures safety and privacy to all members. There are no written safety or complaints procedures. The IHS has an accident book and is in the process of preparing a safety statement.

The IHS has internal reporting mechanisms in the form of regular staff meetings and written monthly staff reports. The organisation had a strategic planning meeting in 1996, which was facilitated by an independent person. Members are occasionally asked for their views on the services of the organisation. Each year, following the annual general meeting the committee evaluates the activities of the previous year and sets out priorities for the current year. There is a staff evaluation once a year.

## **PREMISES**

The IHS is located on the top floor of an office block in central Dublin. The offices comprise main office, kitchen, boardroom and five single offices including a meeting room and counselling office. Disabled access is by lift. Toilet facilities are not fully accessible. There are drop-in facilities from 10.00 am to 5.00 pm, Monday to Friday.

## **SERVICES**

### **INFORMATION SERVICES**

#### *To members and families*

The IHS provides information to parents of children from the time of diagnosis. The IHS circulates a regular newsletter and provides information on treatment and on social welfare services. It operates a helpline from its offices and answers queries from members. The IHS organises seminars for members to keep them up to date on all aspects of haemophilia care. It gives advice on travel for people with haemophilia. The IHS also operates a wide-ranging HIV, AIDS and hepatitis C information service for members and others.

### *Public awareness*

The IHS is committed to targeted public awareness of haemophilia. It has sent information packs to general practitioners (GPs), to every secondary school in the country, to libraries and hospitals, including maternity units on request. Posters outlining what to do if a person with haemophilia presents for treatment were sent to every hospital accident and emergency department in the country. The society staff respond to many requests for information from school students and present information days to schools when requested. General information packs are sent out when requested.

Its media campaigns have, in the main focussed on the society's perspective on the ramifications, personal, familial and societal of the use of contaminated blood products in the treatment of haemophilia. It has also run a number of campaigns to raise funds through the media.

### *Conferences*

The IHS assists other countries worldwide with information. Representatives of the IHS are often requested to visit other countries to share expertise or present lectures particularly at European and world meetings.

### *Publications*

The IHS produces an annual report and a newsletter 4 times per year. It circulates a fact sheet when issues pertinent to members arise. It has published a detailed booklet called *Blood product policy* which sets out the minimum requirements for blood product use, a booklet on bleeding disorders in women, a booklet on hepatitis C and haemophilia, a report *Aids, haemophilia and the government*, which examines the facts surrounding the infection of people with haemophilia with HIV and their consequences. It has also published a 30<sup>th</sup> anniversary booklet. It holds a wide range of publications which are available for perusal at its offices, including reports of the World Federation of Haemophilia, which is located in Canada.

### *Research*

The IHS does not have a distinct research commitment. It occasionally funds external research.

## **EDUCATION SERVICES**

The IHS provides a grant of £1,500 per annum to 1 third level student with haemophilia per annum. This grant is designed to assist with costs of attendance.

## **MEDICAL/NURSING/THERAPEUTIC SERVICES**

Since 1990, the IHS operates a 24-hour emergency service which is available throughout Ireland. This service consists of a dedicated 'phone line in Dublin, to which a home care team respond immediately, going to the family or individual in question and remaining with them until the crisis has resolved. Typically, crisis intervention calls come when a person with haemophilia is dying from AIDS or from the effects of hepatitis C. Part of this service includes laying out the dead body, so avoiding the use of body bags and sealed coffins. The IHS staff will also attend at any hospital to be with a person with haemophilia who is in distress.

### *Holistic weekend*

The IHS runs a holistic weekend each year for members affected by HIV or hepatitis C and for anyone who has been bereaved. This weekend focuses on alternative therapies such as hypnotherapy, aromatherapy, holistic massage, shiatsu and acupuncture.

### **SUPPORT SERVICES**

The IHS provides support to every person with a bleeding disorder and to their families. IHS staff will visit the home when requested, in the case of a newly diagnosed child or in time of illness.

### *Cork mothers' group*

In Cork, a mother's group meets from time to time and a network of support exists between members. Families with haemophilia in the Dublin area provide a hospitality network. This involves individual Dublin families providing overnight accommodation for families from other areas while they visit clinics or hospitals in Dublin.

### *Counselling services*

The IHS has 1.5 full-time counsellors who are based in the national office in Dublin. These counsellors provide ongoing support and therapy for individuals, families, couples and groups. Some counselling is undertaken by 'phone. A drop in service is provided. These counsellors will also travel anywhere in Ireland to an individual or family in distress.

The IHS part-funds a counsellor at Cork Regional Hospital who provides services to people with haemophilia and their relatives in the Cork region.

### *Spiritual support*

The IHS also provides spiritual support, including memorial services for members.

### *Financial support*

The IHS provides hardship grants at Christmas, at first communion and confirmation, and to provide accommodation for parents with children in hospital and for other needs as they arise. The IHS gives financial support to families who may wish to avail of second opinions by assisting in travelling and related expenses.

The IHS also provides mini-calls for parents of children at school, so that the parents can be alerted in case of an accident, for the provision of hospital beds, chairs, wheelchairs, special pillows and tens machines (for the relief of pain) to people with haemophilia who are terminally ill and living at home.

### *Support to people with haemophilia in developing countries*

The IHS has been involved in a twinning project with the Haemophilia Society of Belarus. This provided nine children from Belarus a holiday in Ireland, during which time they were assessed by Irish medical specialists and given prophylactic treatment. The IHS is currently twinned with Hungary in a similar venture.

## **RECREATION SERVICES**

The IHS provides a Christmas party and evening social gatherings. Each year, members in Cork and the surrounding areas have a family day out.

### *Holidays for children*

Children with haemophilia attend the Hole in the Wall Gang camp in Barrettstown, Co. Kildare. This is a summer camp sponsored by Paul Newman. The IHS also has a youth activity weekend organised for boys less than 18 who have been infected with hepatitis C. Leaders and a counsellor accompany the group.

## **ADVOCACY SERVICES**

The IHS is the advocacy body for all people with haemophilia and other bleeding disorders. The organisation is in direct and regular contact with politicians, health boards and government departments to ensure the best services are available to everyone and to seek an equitable resolution of the ongoing problems for its members and their families resulting from the use of contaminated blood products.

The IHS makes representations on behalf of members to ensure their social welfare, housing and other entitlements. It will often accompany members who were infected with hepatitis C when they attend the compensation tribunal. It will represent members' interests at the Tribunal of Inquiry which was set up to establish the circumstances of infection of people with haemophilia with HIV and hepatitis C.

### *Direct action*

In 1991, friends of the IHS fielded four single issue candidates in the local government elections and conducted an intensive media campaign to ensure adequate settlement of outstanding claims in relation to HIV infection. It was part of a strategy which led to an additional £8m. being made available from the State. This sum allowed people to desist from litigation and to cope with the end stages of disease.

### *Links with other organisations*

The IHS is represented on many external bodies including: Hepatitis C Consultative Council, Disability Federation of Ireland, Inherited Disorders Organisation, Children in Hospital, European Haemophilia Consortium, World Federation of Haemophilia.



# IRISH KIDNEY ASSOCIATION

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Website: [www.ika.ie](http://www.ika.ie)

CEO: Gerard Sweeney

## INTRODUCING THE IRISH KIDNEY ASSOCIATION

The Irish Kidney Association (IKA) was formed in 1978, by people with kidney disease, for themselves and their families. It is the only Irish organisation working solely in the interest of patients with chronic renal disease. The prime role of the Irish Kidney Association is to support patients and their families and to help them live as normal a life as possible. It provides information on kidney diseases, associated medical scenarios and social benefits and entitlements. It provides help to newly diagnosed renal failure patients, as well as continuing help to those already being treated.

An important, additional purpose of the association is to support and encourage research into the incidence, prevention and treatment of kidney disease. In providing funds for research into kidney diseases, the IKA acts as a catalyst in pushing forward the boundaries of diagnostics and treatment in the area of nephrology. The association also aims to foster a better understanding and knowledge of this major health problem, through public and professional education.

## KIDNEY FAILURE

People of all ages may suffer kidney failure. In this country each year, about 170 people arrive at the stage of terminal renal (kidney) failure and will die within a few weeks if something cannot be done to replace the function of their now dead kidneys.

Chronic nephritis accounts for more than 60% of the deaths from terminal kidney failure. This is a persistent destructive inflammation affecting both kidneys simultaneously and equally. The inflammation of chronic nephritis occurs because the body is producing anti-kidney substances which continuously attack and destroy the cells of the organ and healthy tissue is replaced by useless scars.

Unlike the other great killing diseases such as cancer and coronary heart disease, chronic nephritis is predominantly a disease of the young, developing most frequently in the first three decades of life. Because of its often slow and insidious course, it may not be recognised until extensive damage has occurred. Young men and women are admitted in the final stages of kidney failure as a result of a process which has been present for 10 or 15 years. Yet they may have carried out hard, manual work within a matter of weeks prior to admission into hospital. Research has given some significant and important advances in recent times. However, there is little hope at present of an important breakthrough in attaining prevention or cure of the disease.

Other causes of kidney failure include continuous urinary tract infections, systemic diseases and hereditary diseases such as polycystic kidney disease (PKD). This is a more common condition than cystic fibrosis or muscular dystrophy. PKD affects both kidneys causing them to enlarge with fluid-filled cysts. It is the progressive growth of these cysts that may result in end-stage kidney failure. Research into PKD continues and there appears to be a possibility of a major breakthrough in this area.

## **MEMBERSHIP AND BOARD STRUCTURE**

The total countrywide membership is approximately 2,500 and comprises transplant patients, haemodialysis patients, peritoneal dialysis patients and also family members and carers of kidney patients. The IKA has 22 branches throughout the Republic in Carlow, Cavan/Monaghan, Clare, Cork, Donegal, Dublin east/Wicklow, Dublin north, Dublin south, Galway, Kerry, Kildare, Leitrim, Limerick, Longford/Westmeath, Louth/Meath, Mayo, Offaly/Laois, Roscommon, Sligo, Tipperary, Waterford/Kilkenny and Wexford. Each branch has a local committee and officers. These branches are the chief area of contact for patients and their families.

The IKA is a company limited by guarantee and its charity number is CHY: 6327. The IKA has a governing council of 6 members and a national executive committee of 18 representing all parts of the country, with a mix of patients and non-patients. The board meets 10 times a year.

## **INCOME AND EXPENDITURE**

Statutory funding, including from the health boards, comes to approximately £25,000 per year. As a voluntary body, the IKA depends mainly upon fundraising to match its major commitment to finance medical research and public education, the issue of multi-organ donor cards and to support the organ donor. Its fundraising activities provide approximately £400,000 per annum.

The IKA spends about £200,000 each year on donor awareness campaigns. It spends about £150,000 on patient support services and the same amount on research and equipment. It also spends about £25,000 on respite services. It recently spent £500,000 as part of a once-off project to develop a renal transplant support centre.

## **STAFF**

The IKA employs 4 staff members, including a chief executive officer, 2 secretarial and administrative staff and 1 patient support officer. It also employs additional staff on part-time or contract bases as required. The IKA does not participate in the CE programme.

## **PREMISES**

IKA headquarters is in a 2-storey house in Ballsbridge, Dublin 4. The offices consist of a large general office, meeting rooms, kitchen etc.

# **SERVICES**

## **INFORMATION SERVICES**

The IKA disseminates information on kidney diseases to new patients and their families, especially with regard to the financial and social effects of kidney failure. It has an extensive website [www.ika.ie](http://www.ika.ie). The IKA provides community health education on the effects of chronic renal failure. An informational video is available free for clubs and schools.

### *Donor cards/public awareness*

The IKA distributes organ donor cards nationally. It organises national donor campaigns once a year and promotes public awareness all year round through national advertising.

### *Publications*

The IKA produces a wide range of free information leaflets, booklets and videos for children and adults about kidney disease, haemodialysis and kidney transplant. It also has brochures and leaflets dealing with kidney-associated diseases including polycystic kidney disease, Alport's syndrome, anaemia in kidney failure, focal segmental glomerulosclerosis, nephropathy, kidney failure and sexual relationships, nephrotic syndrome, renal bone disease, systemic lupus erythematosus and hepatitis C. It has an information sheet on patients' tax allowances, entitlements regarding treatment, travel and other expenses. It publishes *Support*, a quarterly newsletter/magazine, distributed free to members.

### *Research*

The IKA funds practical clinical research projects recommended by its medical research committee or the national executive committee.

## **MEDICAL/NURSING/THERAPEUTIC SERVICES**

The IKA seeks to improve the conditions and quality of dialysis in the treatment units.

### *Medical service funding*

The IKA has funded treatment units for Waterford, Limerick, Sligo, Cavan, Galway and Tralee.

## **SUPPORT SERVICES**

The IKA provides practical assistance to enable the patients and their families to live as near normal a life as is possible. The IKA recognises the importance of psychological and financial support at a traumatic period in a patient's life. Branch officers and members provide a peer support service. IKA officers and staff visit patients in hospital.

### *Counselling service*

The IKA provides limited counselling at Donor House, particularly in relation to hepatitis C.

### *Financial support*

The IKA may assist with the installation cost of a telephone for new dialysis patients. Patient aid is available in emergencies to cover costs such as electricity, telephone, clothing and travel.

## **RECREATION SERVICES**

### *Holidays*

The IKA provides free holidays for members at its apartment complex at Tramore. The IKA helps members requiring dialysis facilities to arrange foreign holidays. It sponsors social and sporting events for all kidney patients.

## **ADVOCACY SERVICES**

As the only organisation representing the views of Irish kidney patients, the IKA continually campaigns on their behalf. A principal aim of the IKA is to improve allowances and medical standards for patients and their families. It also campaigns for increased numbers of dialysis units in the line with modern practice and for the appropriate rehabilitation urgently required for

transplant recipients if they are to overcome their trauma and return to normal living. The IKA will negotiate with the statutory or financial services on behalf of the patient and their family.

*Links with other organisations*

By joining with other statutory and voluntary organisations, the IKA helps in furthering the aims of all patients with chronic illness and improving their quality of life. This ongoing activity covers a wide variety of areas, including contact with government departments, health boards, hospitals, renal units and many other agencies.

The IKA is represented on the boards of CEAPIR , the European Federation of Kidney Patients, the Inherited Disorders Organisation (IDO), the Irish Disabled Sports Association (IDSA). The IKA is a member of Mobility International (MI), European Public Health Alliance (EPHA), World Transplant Games Federation (WTGF), CNEASTA ,the Irish council for training and development and employment for person with disabilities, and Disability Federation of Ireland (DFI).

# IRISH MOTOR NEURONE DISEASE ASSOCIATION (IMNDA)

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## INTRODUCING THE IRISH MOTOR NEURONE DISEASE ASSOCIATION

The Irish Motor Neurone Disease Association (IMNDA) was founded in May 1985 and began to employ staff in 1989. It provides practical support to people with motor neurone disease, their families and care givers. It seeks to break their isolation by giving a long-term commitment and response to families. It also supports ongoing research into the causes and treatment of motor neurone disease.

## MEMBERSHIP AND BOARD STRUCTURE

The IMNDA has a mailing list of 2,300 people. Membership of the IMNDA is free to people with the condition. At present, approximately 200 members are in receipt of services. In addition, the IMNDA has approximately 400 fee-paying members. There is no formal branch structure but support groups exist in most counties.

The IMNDA is a company limited by guarantee. Its charity number is CHY: 8510. The board of directors has 18 members, including 9 officers. There is no formal rotation of the board which meets 5 times per annum.

## INCOME AND EXPENDITURE

The Irish Motor Neurone Disease Association spends about £500,000 per annum. In 1998, the IMNDA obtained £77,000 from the Department of Health and Children, a sum which included £40,000 in national lottery allocation. For the year 1999, the departmental subvention has fallen to a total of £20,000 for the year. The IMNDA receives approximately £24,500 from health board sources (1998 figures: Eastern - £9,870, Midland - £1,000, Mid Western NIL, North

## MOTOR NEURONE DISEASE

Motor neurones carry nerve impulses from the brain and spinal cord to the muscles of the body. Motor neurone disease (also sometimes called amyotrophic lateral sclerosis (ALS)) is a degeneration of these neurones. Depending on the exact location and extent of the degeneration, a person with the condition experiences progressive symptoms of weakness and wasting in various muscle groups, particularly in the upper and lower limbs and the face, mouth and throat. Motor neurone disease does not affect the intellect. The cause of motor neurone disease is unknown.

Most people with the condition are aged 50 years or older, but occasionally younger people are diagnosed. In general, and with some notable exceptions, people with motor neurone disease experience ongoing and progressive problems over a period of between 1-5 years.

At present, no treatment exists to stop the progress of the condition, although a significant breakthrough has been made recently with a drug that increases life expectancy in many cases. Other drug treatments can help to decrease muscle stiffness. People with motor neurone disease benefit from the specialised services of neurologists, physiotherapists, occupational therapists and speech and language therapists. In the latter stages, people benefit from various appliances to improve their comfort and to increase their communication capacity.

Eastern NIL, North Western - £5000, Southern - £1,000, South Eastern - £2,000, Western - £5,500). The IMNDA receives £16,000 per annum from the RPR drug company to assist in employment of a liaison nurse. More than 70% of all IMNDA expenditure (£360,000 approx.) comes from donations, bequests and fundraising. The main fundraising means include sponsorships for the mini-marathon, grand draws, church gate collections and a climb of Croagh Patrick. The IMNDA does not participate in the CE programme.

#### *Expenditure*

The IMNDA spends approximately £182,000 per annum on purchase and maintenance of medical aids and appliances. In 1998, it spent £45,000 on the storage and transport of these appliances. It spent £36,000 on nursing home care assistance and £3,000 on counselling services. Core staff costs came to £78,000 in 1998, with £39,000 in employer-related payments. The association also funds research projects to the value of up to £20,000 per annum.

#### **STAFF**

The IMNDA has 5 staff members, 1 of whom works part-time. All staff are administrative and have relevant skills/qualifications. In addition, the 18 committee members act as volunteers. The IMNDA also has a network of volunteer fundraisers throughout the country.

#### *Training, monitoring and evaluation procedures*

The IMNDA operates no accredited or in-house induction or training programmes, but has a slow induction period for new staff. The association has a high staff retention rate. Safety, monitoring or complaints procedures in relation to direct staff/client interaction are not relevant to the work of the organisation. Informal internal reporting mechanisms are sufficient. The IMNDA has never undertaken any independent or internal review of its operations or activities, in part due to lack of financial resources.

#### **PREMISES**

The IMNDA has 2 offices (with full disabled access) and a small store in Carmichael Centre in Dublin. The association has its own computers and access to a fax service. The IMNDA intends to move premises to Coleraine House, Dublin.

## **SERVICES**

#### **INFORMATION SERVICES**

The IMNDA provides a primary information service through its freephone/helpline. Staff answer general and specific queries about motor neurone disease and seek to provide clear, non-directive, supportive information and advice.

The IMNDA acts as an information and contact source for home-based care services for people with motor neurone disease. The IMNDA has a list of caregivers and home service agencies. The IMNDA will assist in payments for these services, when necessary.

### *Public awareness*

The IMNDA has held information/study days on topics related to motor neurone disease, attended by the general public, people with the condition and their relatives and medical personnel. The association also runs an awareness week, during which local support groups are encouraged to hold an event and to gain local media exposure. The IMNDA staff give talks/lectures to nursing students and staff and other groups on request.

### *Publications*

The IMNDA has a number of brochures and booklets which it distributes on request including a brochure giving basic information on motor neurone disease and on the work of the association. This was produced with the assistance of the Health Promotion Unit of the Department of Health and Children. The IMNDA also has a series of leaflets on relevant concerns including speech and swallowing, upper and lower limb difficulties. It has produced a booklet called *Living with motor neurone disease*. It produced a brochure in tandem with the drug company RPR. It has sent information to every GP in the country. The association also produces a newsletter called *Connect*, 3 times a year, which it sends to members, their families, interested individuals and health care professionals. The IMNDA does not produce an annual report, but has plans to do so.

### *Research*

The IMNDA keeps abreast of international research developments and has a library of research. The IMNDA provides limited funding for motor neurone research projects undertaken in Ireland. For example, it funded basic research on glutamates undertaken at the Department of Biochemistry in University College Dublin (UCD). At present, the IMNDA is part-funding a psychosocial study of accessing and evaluation of counselling and support services at UCD. It has also given £20,000 to the Royal College of Surgeons in Ireland (RCSI), to assist in funding a project to examine psychological and other quality of life measurements in relation to motor neurone disease.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

The IMNDA provides a clinic liaison nurse, with the financial assistance of the RPR drug company. This nurse was involved in the monitoring of recent drug trials of Riluzole, a product which has been found to give some relief to many people with motor neurone disease. The duties of the nurse include organisation of appointments for attendance at the interdisciplinary neuromuscular clinic held in Beaumont Hospital weekly; personal attendance at the clinic; liaison between the clinic and public health nurses, hospice home care teams general practitioners and IMNDA staff; giving advice, by telephone, on the care and concerns of people with motor neurone disease.

Since 1995, the director of the IMNDA also attends the weekly clinic at Beaumont to meet with people with a diagnosis of motor neurone disease and their families.

### **SUPPORT SERVICES**

The IMNDA operates a freephone helpline. This line often receives calls from people in acute distress following the diagnosis of motor neurone disease for themselves or for someone close to them. All staff members answer the helpline calls and seek to provide support and

encouragement to all callers. The helpline is used by many people for ongoing support. It is also used by occupational therapists, public health nurses and other community-based staff to seek information or assistance for people with the condition in their area.

#### *Informal support networks*

The IMNDA puts families in contact with each other by mutual agreement. These contacts are often long-lived and provide ongoing support to both parties.

#### *Counselling service*

The IMNDA refers members to trained counsellors for personal, group or family therapy on request and will provide funding if required.

#### *Financial support*

The IMNDA supports families financially, insofar as possible and necessary. The association will buy and/or lend equipment to members. The IMNDA provides funding, if required, to facilitate families and caregivers to obtain respite. The IMNDA also assists financially with short breaks and pilgrimages to Lourdes, often facilitated by CASA, the Caring and Sharing Association. The IMNDA also responds to occasional contacts by general practitioners and public health nurses with requests to provide funds for needy individuals with motor neurone disease.

#### *Equipment purchase or loan*

One of the principal activities of The IMNDA is the loan of necessary equipment to people with motor neurone disease. This includes hoists, powered wheelchairs, specialised beds, and computerised communication aids. The association has a member of staff who acts as an equipment coordinator. All of the items available are recorded on an extensive data base. The association rents 2 storage facilities to keep the equipment when not in use and employs a van and driver to deliver equipment to the member's door.

### **ADVOCACY SERVICES**

The IMNDA is the national, non-governmental representative body for people with motor neurone disease and their families. The association is critical of the variability of services obtainable through the regional health care system and campaigns for improved services nationally for people with motor neurone disease. It has a long-term aim to secure medical card provision for people with motor neurone disease. It has ongoing contact with politicians, health board officials and staff in government departments. It also has contact with staff in county councils in relation to house modifications.

The IMNDA will take direct action when necessary. It provides self-advocacy services and encourages all members to claim entitlements from all statutory sources. Given the natural progression of motor neurone disease, The IMNDA considers that people with the condition should receive necessary equipment and appliances as and when needed.

#### *Links with other organisations*

The IMNDA is a member of Disability Federation of Ireland (DFI). It is a member of the Irish Neurological Alliance. It also has ongoing contact with CASA, the Caring and Sharing Association. The IMNDA was a founding member, and held the founding chair of the International Alliance of Motor Neurone Disease/Amyotrophic Lateral Sclerosis Associations.



## IRISH RAYNAUD'S & SCLERODERMA SOCIETY

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### INTRODUCING THE IRISH RAYNAUD'S AND SCLERODERMA SOCIETY (IRSS)

The society was founded in 1988. Since 1992, it has been affiliated to the Raynaud's and Scleroderma Association in the UK and has benefited from the information and research capacity of the larger organisation. The IRSS is committed to providing information and support to people with the conditions and to their families. The IRSS also aims to promote a better understanding of Raynaud's and scleroderma amongst healthcare professionals and the general public. It seeks to raise funds to assist any members in need and to assist medical research. It campaigns for the establishment of a specialist diagnostic, therapeutic and research centre for Raynaud's and scleroderma. The society faces increasing calls from its membership to provide regional support, but the society lacks the funding and the voluntary personnel to respond. Recently, the society has experienced difficulty in obtaining free media publicity.

### RAYNAUD'S AND SCLERODERMA

Raynaud's is the medical name to describe a condition where the small blood vessels in the fingers, hands and/or feet constrict and stop the flow of blood, in response to cold or to emotional stress. When the blood flow stops, the fingers or toes change colour to become white or blue and then red. Up to 20% of a population may have this problem, usually in a mild form. It is more common among women than men. It is not contagious, nor is it hereditary, although there may be a family predisposition.

In severe cases, Raynaud's gives rise to pain and/or numbness in the fingers and problems with other vascular spasms in the internal organs. Severe Raynaud's may restrict a person's ability to perform routine activities of daily living, such as buttoning and opening jars. Keeping warm at night is also important. Attacks of Raynaud's should be avoided or minimised through consistent attention to body temperature, adequate but not excessive physical exercise, rest and a good diet, avoidance of stress and of smoking. In severe cases, special clothing, bedding, warming devices for the hands and feet and appliances to help in performing routine manual tasks may be required. In severe cases, vasodilatory drugs may be prescribed.

Raynaud's phenomenon may be primary, i.e. it may exist on its own without any other underlying cause. It may also be one early symptom of a number of serious systemic conditions, most commonly with scleroderma. About 95% of people with scleroderma also have Raynaud's. However, only about 4-5% of people with Raynaud's develop scleroderma. Because of the seriousness of scleroderma and its relationship with Raynaud's, people with symptoms of Raynaud's should be offered a blood test to check whether there is an underlying systemic cause of the phenomenon.

## **MEMBERSHIP AND BOARD STRUCTURE**

The IRSS has a national register of 1,300, including approximately 450 paying members. It has no branch network. It is a company limited by guarantee. Its charity number is CHY: 9845. The board has 10 members, with no set rotation and approximately 10-12 meetings per year. The society operates no lower or upper age limits on board membership.

## **INCOME AND EXPENDITURE**

The IRSS obtains in the region of £25,000 per annum. Some income derives from trusts such as the Catherine Howard Trust Foundation, the Glorney Trust, People in Need, Ireland America funds and the Monkstown Hospital Foundation. The IRSS has a high reliance on fundraising activities to provide its income. Each year it raises approximately £10,000 -£15,000 through a golf outing in May, sponsorship of participants in the ladies' mini-marathon in June and a bridge tournament in November. Other income sources include donations from private business and from individuals. The IRSS has been in receipt of a small amount of State funding, namely £2,000 from the national lottery fund. The society has recently resubmitted a request for £25,000 funding for the purchase of diagnostic equipment for use in St. James's Hospital, Dublin from the national lottery fund, through the finance unit at the Department of Health and Children.

### *Expenditure*

The IRSS spends approximately £20,000 per annum. This includes £8,175 on wages, including employers' PRSI, £2,500 on newsletters and £1,500 on postage and telephone costs.

## **STAFF**

The IRSS employs a part-time secretary. It also has about 10 volunteers. The society does not participate in the CE programme.

### *Training, monitoring and evaluation procedures*

The IRSS has no training or induction programmes for staff but would be interested to learn about external opportunities, including accredited courses. It has no formal safety or monitoring procedures, any such issues are dealt with informally as required. In relation to volunteers, the society seeks out people with relevant expertise or strengths. It is financially accountable to the Revenue Commissioners and carries out intermittent internal evaluations.

**Scleroderma** was originally recognised as a skin problem. We now know that there may be hardening, not merely of the skin, but of the blood vessels, joints and major internal organs including the kidneys, heart, lungs and bowel. A person with scleroderma produces excessive amounts of collagen which is laid down in the body causing thickening and hardening.

Scleroderma can be difficult to diagnose due to the enormous variability of symptoms and to the differing rates of progress of the condition. Early diagnosis gives a substantially better prognosis due to the effectiveness of existing treatments, which seek to limit the damage done to the major organs. Scleroderma is 4 times more common in women than in men.

The treatment of scleroderma may involve many medical specialities. Drugs can give some relief from some of the symptoms and, more important, can slow or stop progressive problems, if given early enough.

## **PREMISES**

The secretary operates from home. The IRSS uses computer technology. Meetings are held in hotels.

## **SERVICES**

### **INFORMATION SERVICES**

#### *Helpline*

The IRSS operates a helpline at (01) 8481143, operated by a volunteer. Members may telephone for information on a wide range of topics related to their condition. The IRSS applied for a freephone number but was refused.

#### *Seminars and conferences*

The IRSS invites leading medical consultants from Ireland and the UK to address its annual conference on topics of relevance to its members. It has also run regional information events in Cork and Waterford.

#### *Media publicity*

The IRSS runs media campaigns twice yearly in a broad range of national, regional and local newspapers and magazines and on local radio to develop public awareness of the problem of Raynaud's phenomenon in particular. It ran a poster campaign during the winter of 98/99 to highlight Raynaud's as a medical condition. It will run a poster campaign through pharmacies with a similar message in 1999/2000.

#### *Publications*

The IRSS provides literature to people with Raynaud's and/or scleroderma and to their families. Some of this literature it publishes, others it imports through the Raynaud's and Scleroderma Association in the UK. The IRSS does not produce an annual report. It publishes a biannual newsletter which is sent to paid members, some medical personnel and other interested individuals. Information packs are sent to a variety of health professionals including general practitioners, hospital doctors and nurses, final year medical students, physiotherapists, occupational therapists, chiropractors and to health centres.

#### *Research*

The IRSS occasionally provides funds to support research projects.

### **SUPPORT SERVICES**

#### *Members' helpline*

The IRSS operates a telephone helpline at (01) 8481143, operated by a volunteer. This provides information and support to a person with Raynaud's and/or scleroderma or to a relative or caregiver.

#### *Support network*

The society has a support network which enables people to contact others in a similar situation. Volunteers occasionally visit members at home or in hospital.

### *Equipment purchase or loan*

IRSS members experience considerable variation in the availability of necessary equipment through the regional health boards. The IRSS seeks to ensure equity of treatment of all members regardless of where they live. The society operates a welfare fund and supplies equipment which members are unable to obtain through their health board. They must have a letter of recommendation from a suitably qualified medical professional. All members availing of this service are asked for a monetary contribution. The most commonly supplied items include wheelchair head rests, transport access ramps, battery operated heated gloves and socks, heated mattresses and special clothing and heating aids.

### **ADVOCACY SERVICES**

The IRSS is the national representative body of and for people with Raynaud's and scleroderma. It speaks on their behalf to government and to other statutory agencies including the health boards. The IRSS campaigns for the improvement of diagnostic services, in particular for the establishment of a one-centre diagnostic treatment and research unit. At present, many IRSS members are under the care of 5/6 different medical consultants, based in different locations.

The IRSS would wish to see the employment of nurse specialists who would co-ordinate existing services for people with Raynaud's and scleroderma and who could provide them with appropriate information and support. It has direct contact with some medical professionals working in the field, including medical consultants and rheumatology nurses. The society also has contact with individual national politicians.

# IRISH SOCIETY FOR AUTISM

Address: Unity Buildings  
16 lower O'Connell Street  
Dublin 1

Tel: (01) 8744684

Fax: (01) 8744224

E-mail: autism@isa.iol.ie

Website: www.iol.ie/~dary/isa/

Chairman: Dr. James Hayes  
Executive director: Pat Matthews  
Director and secretary: Nuala Matthews  
Service development manager: John Saunders

## INTRODUCING

### THE IRISH SOCIETY FOR AUTISM

The Irish Society for Autism (ISA) was founded in 1963 to provide information and support to families affected by autism, to act as an advocate for people with autism and their families, to increase public awareness of the condition and to provide services for adults with autism. The society seeks to promote the well-being of all people with autism through a comprehensive range of services including full-time care and training to people with autism and their families, and to actively campaign for improved health, educational and social services which are autism-specific. In recognition of their work with people with autism, the executive director of the ISA, Pat Matthews and his wife, Nuala, were the recipients of a People of the Year Award in 1996. The society was declared an overall national winner of the Allied Irish Banks (AIB) Better Ireland millennium awards in January 2000.

The philosophy of the society is a recognition of the individuality of each person with autism, their capacity to benefit from education, training and care, and their entitlement to participate in the development of society in accordance with their individual capacity and dignity. The society develops and operates projects for people with autism which are models of good practice. The society's flagship project, Dunfirth Farm, is a prototype which the society seeks to recreate in a number of additional locations.

### MEMBERSHIP AND BOARD STRUCTURE

The society has an associate membership of approximately 300 families. It has a regional branch network in Dublin, Kerry, Kilkenny, Monaghan, Midlands, Waterford, the west of Ireland and Wexford. Information and advice services are provided to nonmembers.

## AUTISM

Autism is a rare condition which causes lifelong severe problems in communication, social interaction and behaviour. Autism affects 15 in every 10,000 births. Most people with autism are male.

Children and adults with autism have problems in developing imaginative play and may prefer very familiar items around them. Often people with autism have considerable difficulty in communicating. They also have difficulties in social contact and may behave in unusual ways.

About 2,000 Irish children and adults live with autism. To date, no definitive cause has been identified. Children with autism benefit from special education and training, including speech and language therapy. Adults benefit from a supportive and familiar environment.

The ISA is a company limited by guarantee and its charity number is CHY: 5547. The board of management comprises 10 members with 6 meetings per annum. The Irish Society for Autism is a founder member of the International Association Autism Europe (IAAE). The director of the ISA was elected as first vice-president of IAAE and president of the World Autism Organisation.

#### **INCOME AND EXPENDITURE**

The ISA turns over approximately £2m. per annum. It obtains funds from EU sources, from the health boards and from charitable fundraising. Its events include a *Rose week* in October, a gala ball in October, golf outings in May/June, art and wine auctions, a Christmas teddy appeal, Christmas raffles, charity walks and cycles, church gate collections and collection boxes. It has also received funding through the RTE telethon.

#### **STAFF**

The ISA has 70 staff members, of whom 6 are administrative. All have relevant/necessary qualifications. It has 12 CE workers. The society welcomes volunteers.

#### *CE scheme*

The CE scheme has an important role in providing support to the service. The mainstream employment placement rate for CE workers has been high in recent years.

#### *Training, monitoring and evaluation procedures*

The ISA has induction, accredited and other in-house training programmes for staff and CE workers. The society sees value in developing additional, accredited training programmes. The society has written policies and procedures and an internal review system.

#### **PREMISES**

The national office is at O'Connell Street, Dublin. It is computerised and has drop-in facilities. The society has residential facilities at Claregalway, Co. Galway and Galway city, Dunfirth, Co. Kildare, Athboy, Co. Meath, Kinnegad, Co. Westmeath and Kilmore, Co. Wexford.

## **SERVICES**

#### **INFORMATION SERVICES**

The ISA provides specialised information to families affected by the condition. A video and book library, or centre, is available at the head office. The society has a website: [www.iol.ie/~dary/isa/](http://www.iol.ie/~dary/isa/) It organises regional one-day seminars. It produces publicity literature. It funds research into autism.

## **SUPPORT SERVICES**

### *Respite services*

The ISA sees a growing need to provide respite breaks. The society has acquired suitable premises in Ballymurn, Co. Wexford. The facility is an excellent, well-equipped holiday and respite home for parents and children, for groups of children or adults with autism.

## **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

The ISA plans to develop Tig Ronan, Newcastle, Co. Galway as a training and development centre for 8 adolescents who are presently attending other nonspecialist services. The ISA also has training and employment services in its residential communities.

## **HOUSING SERVICES**

The ISA operates a number of residential communities for adults with autism. Dunfirth Farm in Dunfirth, Co. Kildare was the first to be established, in 1982. It provides accommodation and employment for 37 residents. It has about 70 acres and provides vocational training in poultry management, pottery, horticulture and deer farming. The residents grow organic produce with the assistance of EU funding. A retail outlet, Odyssey, has been established in Leixlip village. Trainees at the farm can take part in production, marketing and retailing.

In partnership with the Eastern Health Board, the society runs the Gheel training group in Dublin, which provides residential and day care services for 53 people with autism.

### *Ongoing development programme*

#### Cluain Farm, Kinnegad, Co. Westmeath

The society recently acquired a 30-acre farm at Kinnegad. This property is being developed to provide another centre of excellence for 18 people with autism.

#### Moygrehan House and Farm, Athboy

This is a 30-acre farm in a pastoral setting, with peaceful surroundings suitable for the lifestyle of people with autism. The main house was completely refurbished and opened last year. It accommodates 6 people with autism.

#### Sarshill House, Kilmore, Co. Wexford

This historic house has been completely refurbished and, when opened early in 2000, will provide residential accommodation for 6 people with autism. Some of the outbuildings may be converted into 10 self-contained apartments.

#### Cloonmore Farm, Claregalway, Co. Galway

The society has acquired a 50-acre farm with a bungalow in Claregalway. Following some alterations to the building, it now provides accommodation for 4 people with autism. An expansion will commence soon, to enable the service to include a further 14 people with autism. The farm will undertake all of the usual farm activities and will specialise in the growing and selling of organic herbs.

### Clybaun Heights

A house in Clybaun Heights is home to 2 young people with autism, with another 2 due to join them soon. It is intended that they will live at Clybaun and work either at Cloonmore Farm or in supported employment in the area.

### **ADVOCACY SERVICES**

The ISA is the national non-governmental representative body for all people with autism and their families.



## **IRISH WHEELCHAIR ASSOCIATION (IWA)**

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Clontarf  
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**Fax:** (01) 8333873

**E-mail:** [admin@iwa.ie](mailto:admin@iwa.ie)

**Website:** [www.iwa.ie](http://www.iwa.ie)

**CEO:** Seamus Thompson

**Also:** Cuisle  
Donamon  
Co. Roscommon

**Tel:** (0903) 62277

**Fax:** (0903) 62426

**E-mail:** [cuisle@iwa.ie](mailto:cuisle@iwa.ie)

**Website:** [www.cuisle.com](http://www.cuisle.com)

**Manager:** Gerry Sharvin

### **IRISH WHEELCHAIR ASSOCIATION MISSION STATEMENT**

The Irish Wheelchair association aspires to be the leading organisation in Ireland of and for people with physical disability; giving voice to the demands of all members and taking action at local, national and international levels in order to achieve these objectives.

### **INTRODUCING THE IRISH WHEELCHAIR ASSOCIATION (IWA)**

The Irish Wheelchair Association (IWA) is a voluntary organisation of people with physical disabilities. It was founded in 1960 by a small group of wheelchair users who wanted to do something about their exclusion from all aspects of life. In particular, they identified their physical exclusion from inaccessible buildings and transport as a core concern, as it meant that they could not avail of education, training, employment or social life. Many benchmark service developments have been undertaken by the IWA. These include its extensive care attendant scheme, its peer counselling services, its brokerage of a personal assistant (PA) service since 1995 and its central role in the establishment of Cuisle, the first national respite, holiday and residential training facility for people with physical disabilities.

The IWA sees its role today as representing people with disabilities, advocating with members on issues identified by members and providing a range of services and programmes. Its main concerns are the inadequate and inequitable provision of services and equipment to people with physical disabilities to support their participation in society. The IWA contextualises this problem in terms of equality, access and inclusion within a social rights perspective.

## **MEMBERSHIP AND BOARD STRUCTURE**

The IWA has a membership of 8,000 people and has several thousand supporters and volunteers. It is a democratically-run organisation. Members are involved at every level through 50 branches, 4 regional councils, a national council and a national executive.

The IWA is a company limited by guarantee. Its charity number is CHY: 5393. The national executive comprises 16 members, including 2 from each regional council, 3 members elected by the national council and 3 co-opted staff members. The national executive meets 6 times a year.

## **INCOME AND EXPENDITURE**

Each branch has its own structure and financial accounts and is audited separately. All of the figures presented here are for 1998 and refer to central organisation expenditure only. In that year, government grants, health board subventions and European Social Fund (ESF) income came to a total of £5,940,291. Other income from charitable donations, workshops' sales, charity shops and investments came to a total of £1,422,494. The IWA finds it increasingly difficult to raise funds from charitable giving. Among its many fundraising ventures are a Christmas and Easter hamper/teddy campaign, a sponsored walk, national car raffle, golf classics, charity shops in Rathmines, Clonakilty, Athlone, Dungarvan and Tuam, church gate and flag days and Christmas card sales.

### *Expenditure*

The IWA spent £6,971,246 in 1998. This included £4,310,973 on its members' resource programmes, £567,947 on personal assistant services and £430,493 on care assistant services. The driving school cost £237,245.

## **STAFF**

IWA employs more than 150 full-time and 650 part-time staff members. These figures include 380 people employed in local communities sponsored by the FAS CE programme, 86 PAs attached to CE schemes and 180 care attendants. Other people work in community development, or as instructors, trainers, driving programme or respite staff. A small number work in finance and administration. The IWA also has a number of wheelchair technicians and a sports development staff.

### *CE schemes*

The IWA has 28 CE scheme projects located throughout the country. The overall cost is in the region of £3m in 1999 (preliminary figures). The IWA considers that CE worker participation is core to its operation, particularly in relation to the provision of transport and resource programmes. To date, CE workers have had a 48% progression to mainstream employment or education.

### *Volunteers*

Volunteers in the IWA assist with fundraising, branch programme, services and lobbying.

### *Training, monitoring and evaluation procedures*

Regular induction programmes take place for all core staff and CE workers. The IWA has 3 staff panels to examine and implement all aspects of internal training. These include qualified

lifting and handling instructors, disability awareness trainers, care skills and safety trainers. The IWA also has 4 regional trainers to implement core training programmes and job specific training inputs. Training programmes are accredited through FAS at City and Guilds Level I. The organisation also supports staff to participate in external training programmes relevant to their work. The IWA introduced a safety statement and standards of practice manual in 1997 and is currently updating this resource.

The IWA has undertaken a branch/volunteer review and renewal process in 1998. It also has a series of consultations with members and staff on issues such as the development of models of practice for resource centre programmes. In 1998, the personal assistant (PA) service, brokered through the IWA was independently evaluated. Individual services have been reviewed, most recently *Interact*, the motor advice, assessment and tuition service (MAATS) and the sports service. All staff comply with weekly and monthly written reporting requirements. Many services have users' consultative/advisory groups.

### **PREMISES**

The IWA national headquarters is an extensive, fully accessible building with numerous offices. The operation of the association is computerised. There are drop-in and meeting room facilities. In the grounds of the headquarters there is independent living accommodation for people with disabilities. Cuise is located on the banks of the river Suck and is surrounded by spacious and pastoral grounds. The IWA also has a large number of premises in local areas throughout the country, from which it operates its resource centres. It has a range of housing for people with physical disabilities in various locations throughout the country.

## **SERVICES**

### **INFORMATION SERVICES**

The IWA's information and advice services are available nationally through its community development staff and resource centres. The IWA has promotional videos of its work, *People first* and of Cuise.

#### *Seminars*

The IWA runs seminars on a wide range of disability topics.

#### *Disability awareness*

The IWA, in partnership with the National Council for the Blind of Ireland and the National Association for Deaf People has developed a joint disability awareness workshop. This training is available to health board staff, to college staff and students and practising architects.

#### *Public awareness*

The IWA promotes awareness of disability issues, locally and nationally. The IWA runs media campaigns, particularly before the annual government budget.

### *Interact*

The IWA participates as a specialist support agency in the Department of Social, Community and Family Affairs' community development project, through its agency, *Interact*. This provides information resources to individuals and groups nationally.

### *Publications*

The IWA has published a number of seminal reports in the past 10 years. For example, *People first (1994)* was a survey of members' needs which influenced policy and service development. It has published booklets on participation in local development. The IWA publishes *Spokeout* and *On Track* magazines for adult and child/teenage members and *Sportabout*, a compilation of the sports activities with the organisation. It also publishes an extensive annual report.

In 1998, the IWA set up a pilot programme with the National Social Services Board (NSSB) to develop fact sheets. This led to the publication of guides on housing, grants and entitlements, support services, private transport, holidays in Ireland and abroad. The IWA assisted in developing a disability awareness brochure for general practitioners (GPs) in the Eastern Health Board region. It has produced a code of practice for information service provision and an access checklist for use by the general public and by housing and environmental planners. Cuisle produces an information and booking brochure. A number of local IWA groups produce newsletters and publications.

### *Research*

The IWA has a small, ongoing research commitment.

### *Planned information services*

The IWA plans to train more regional information staff in 2000. It also plans further publications based on common queries from its members.

## **EDUCATION SERVICES**

The IWA provides a range of educational programmes, including adult literacy, in its centres. The IWA provides transport for disabled students to the National University of Ireland (NUI) Cork campus.

### *Driving schools*

In 1998, IWA driving instructors provided more than 5,000 hours of driving instruction throughout the country. All instructors are certified through the driving instructor register. Residential driving courses are now held at Cuisle.

As part of its motor advice, assessment and tuition service (MAATS), the IWA issues parking card to passengers and drivers with disabilities. The IWA also operates a driving assessment service. This provides drivers with advice on the suitability of vehicles and equipment.

## **SUPPORT SERVICES**

The IWA operates a wide range of support services under the auspices of assisted living services and through its resource centres. Informal support networks exist through the branches. The IWA community development officers facilitate local and regional groups. Youth and carers'

groups are held in Cuisle and elsewhere during the year. The IWA runs an outreach programme, in association with the Inishowen Partnership, based in Clonmany.

#### *Assisted living services*

These include care attendant services and personal assistant services. The IWA operates one of the largest care attendant services in the country. The IWA provides a care attendant who works in the home of the disabled person for a limited number of hours per week. This service allows the person who usually cares for the disabled person to have time to do other tasks or to take a break. It also helps the person with a disability with personal care and/or mobility.

**Number of hours of care assistant and personal assistant service provided through the IWA in the health board regions in 1998.**

<b>EHB</b>	<b>MHB</b>	<b>MWHB</b>	<b>NEHB</b>	<b>NWHB</b>	<b>SEHB</b>	<b>SHB</b>	<b>WHB</b>
36,000	15,448	6,000	3,300	16,400	27,200	6,000	14,000

#### *Resource centres*

The IWA has 40 regional and local resource centres which run a range of courses designed to stimulate members to learn new skills. The aims of these centres are to link people with physical disability to everyday life, to provide opportunities to develop new skills, to give support and social contact and to offer respite for the carer. Among the many courses on offer are personal development, specialised men's groups, leadership courses, personal care and hygiene, self-advocacy, drama, pottery, visual and other arts, and flower arranging.

Resource centres operate in Athy, Ardee, Arklow, Athlone, Bandon, Belmullet, Carlow, Carrick-on-Shannon, Castlebar, Clane, Clara, Clogh, Cloghran, Clonakilty, Cork, Dublin, Dundalk, Dungarvan, Ennis, Galway, Kilcormack, Killarney, Kilkenny, Kinsale, Limerick, Listowel, Longford, Mallow, Manorcunningham, Midleton, Mullingar, Navan, Roscommon, Roscrea, Skerries, Skibbereen, Tipperary, Tuam, west Dublin, Waterford, Wexford.

#### **IWA RESOURCE CENTRES**

Information on addresses, contacts and telephone and fax numbers are available on the IWA website and through the headquarters at Blackheath Drive, Dublin 3.

#### *Peer counselling service*

The IWA operates a peer counselling service in partnership with the National Council for the Blind of Ireland (NCBI). As part of this overall programme, the participant organisations have developed a procedures manual for peer counselling and have planned training courses which are accredited to diploma level.

#### *Respite services*

The IWA operates Cuisle, at Donamon, Co. Roscommon. It has 45 bedrooms, many with ensuite and TV, communal TV and relaxation areas, gymnasium, tennis courts, sports field, coffee shop and lounge. All of the facilities are accessible and the centre has overhead and portable hoists, personal help call buttons throughout, adapted transport and centre-based assistance if required. The centre offers seminar and conference facilities. A laundry service is available. Local amenities are accessible and coarse fishing is also available. This centre caters for all types of individual, family and group holidays/programmes. Guests may opt for bed only,

B&B, half or full board accommodation. The IWA provides a transport service to Cuisle from anywhere in the country. The new multipurpose centre in Kilkenny has respite accommodation. The IWA has plans for a respite centre in Clontarf, Dublin, 3 in 2000.

#### *Visiting services*

Staff and volunteers undertake home visits to members.

#### *Financial support*

Branches provide financial support to individuals, on a needs basis. People availing of respite breaks are given financial support when necessary.

#### *Equipment purchase or loan*

The IWA has a commercial mobility division. The IWA operates a wheelchair purchasing service with a showroom and assessment centre. This centre also sells cushions, walking aids and general appliances. The IWA is the exclusive contractor to the Eastern Health Board for the servicing of electric wheelchairs and scooters. The IWA equipment sales staff run intensive product knowledge seminars for occupational therapists and purchasing officers in the health board regions. The IWA operates an extensive wheelchair lending service.

#### *Transport services*

The IWA offers a transport service for branch members in many parts of the country through its branches. This gives members access to clinics, activities and resource centres and to Cuisle.

### **RECREATION SERVICES**

#### *Sport*

The IWA is the main governing body in Ireland for sport involving people with physical disabilities. It holds sporting events throughout the country. It promotes sporting participation by its members in a variety of sports for disabled and mainstream sports. The IWA raises funds to send teams to international sporting competitions.

### **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

The IWA has recognition from the National Accreditation Committee (NAC) for its training centre in Clontarf. This centre offers 2 programmes: a Training Opportunities Programme (TOPs), funded through the State exchequer and *SkillBase*, a Level 1 programme, funded through the European Social Fund (ESF). This latter is a full-time course at Clontarf, Dublin 3. The National Rehabilitation Board (NRB) monitors both of these programmes. The IWA also provides on-job training.

In 1998, the IWA set up a simulated business practice course, held in Cuisle. This programme is an experiential learning opportunity whereby day and residential trainees work on developing a business in the leisure industry. This programme is supported by the EU Horizon Roscommon Partnership, the south mid-Roscommon Leader company and Roscommon Enterprise Board.

The IWA offers accredited training to community employment workers and assistant services staff.

### *Access consultants*

The IWA, in a joint north-south project with NICOD and ASBAH, with the support of the Ireland Funds and the Peace and Reconciliation programme, undertook a project in which 20 people with disabilities, from both sides of the border, trained as access officers. In 1999, IWA staff cooperated with the National Council for the Blind of Ireland (NCBI) and the National Association for Deaf People (NAD) to advise on revisions of part M building regulations.

### **HOUSING SERVICES**

The IWA has a multipurpose facility in Kilkenny, which provides 13 living/respice/training apartments. This development was supported by the Department of the Environment, and the South Eastern Health Board, through Kilkenny County Council.

The IWA also has independent living apartments in Kilkenny, Galway, Athy, Clane and Clontarf. It plans to establish apartments in Limerick and Belmullet.

### **INDEPENDENCE SERVICES**

IWA policy supports a "clearinghouse" approach to PA and home support services nationally. The IWA, in partnership with the EHB, operates a PA service. The IWA acts as a broker in the arrangement. This service provides PAs to 58 leaders.

### *Independent living training programme*

The IWA also runs an independent living training programme in Dublin, Galway, Athy, Co. Kildare and Kilkenny. In this service, people are offered support by community development staff and occupational therapists and are connected with appropriate assistant/home help services, insofar as possible. The IWA is examining proposals for an independent living programme in Erris, Co. Mayo.

### *Community development*

The IWA's *Interact* is the specialist support agency to the Community Development Programme of the Department of Social, Community and Family Affairs on disability. A number of practical guides and other support materials have been published in partnership with the National Social Services Board (NSSB). The IWA community development teams now cover every county. They work in partnership with members, local development agencies and the health boards.

### **ADVOCACY SERVICES**

A key aim of the IWA is to influence change by highlighting the issues which prevent people with disabilities from participating as full and equal citizens in society. The IWA lobbies government and public agencies for improvements in services at local and national level. This includes action on income, housing, employment, access, mobility and social services.

The IWA has ongoing contact with the Department of Health and Children. It has made submissions to the Department of the Environment and regional local authorities on access, transport and the disabled person's housing grant scheme. It presses the Department of Social, Community and Family Affairs to improve inclusion using the Community Development Programme (CDP). It has approached the National Social Services Board for the development

of information services. It is in dialogue with FAS in relation to community employment projects, the need for change of the criteria and about accredited training. The IWA has contacts with Area Development Management (ADM) and the local partnerships in an effort to promote the inclusion of people with disabilities in local communities. It has also approached Leader companies and Udaras na Gaeltachta for various locally-based inclusion programmes. It asks Vocational Education Committees (VECs) for tuition/course funding locally.

The IWA makes pre-budget submissions and provides a critical commentary on budget decisions. Through *Spokeout*, one of its regular magazines, the IWA presents a critical perspective on existing and forthcoming legislative and financial policy. The IWA has resource centres throughout the country. These provide a wide range of services to members, with a focus on self-advocacy.

#### *Direct action*

Since 1998, it has organised an extensive lobbying campaign with a focus on the budget. This has included a direct action, pre-budget, public march. It also ran a successful campaign on aids and appliances which led to the allocation of £1.5m to the IWA in the 1998 budget. IWA lobbying campaign strategies include lobbying of regional health board members and of local politicians. Members of the IWA attend the Ard Fheiseanna of the two main parties as observers and promote the IWA issues. It also runs campaigns on the carer's allowance and the disabled person's housing grant.

#### *Links with other organisations*

The IWA is affiliated to Disability Federation of Ireland (DFI), Disabled Persons International, Irish Charity Tax Reform Group, the Not-for-Profit Business Association and Transport for All.

#### *Representation on State and non-statutory boards*

IWA members have places on various disability interest subcommittees in the following organisations: Disability Federation of Ireland, National Parents' Council, Eastern Health Board's women and disability committee, the national access committee, on each of the health board coordinating committees, Dublin Transport Organisation committee, Paralympic Council of Ireland, Sports Council of Ireland, Irish Charity Tax Reform Group, National Lottery compensation committee, Association of Driver Educators for People with Disabilities (ADEPT), MS Care Centre advisory committee, FAS, Action for Disability Horizon project, Not-for-Profit Business Association and Disabled Persons International.



## THE JACK AND JILL CHILDREN'S FOUNDATION

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(045) 894538

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Contacts: Jonathan Irwin  
Mary Jo Guilfoyle  
Margaret Naughton

### INTRODUCING THE JACK AND JILL CHILDREN'S FOUNDATION

The Jack and Jill Children's Foundation was established, with charitable status, in 1997. It seeks to provide information, support and financial assistance to families with a newborn, infant or young child (typically under the age of 4 years) who has significant developmental difficulties or delays and who requires intensive nursing care.

The Jack and Jill Children's Foundation promotes early intervention home respite and campaigns for the provision of statutory services to ensure the welfare of children under the age of 4 years. It has persuaded the Revenue Commissioners to extend certain discretionary income tax rebates, available to parents of older children in similar circumstances, to parents of children under the age of 2 years. It argues for the extension of the Domiciliary Care Allowance (DCA) to families with a severely developmentally delayed child under the age of 2 years. It also seeks a constructive dialogue with the maternity and paediatric units in the country to facilitate appropriate referral to its services. The Jack and Jill Children's Foundation intends to extend its campaigning and public awareness role in the near future.

### BABIES WITH SEVERE DEVELOPMENTAL DELAY

Every year in Ireland, unknown numbers of babies are born with severe developmental difficulties. At present, the Irish health service provides little if any assistance to this group of children, or their parents, until the child reaches the age of 4 years.

If, and when, their medical condition is stable, these infants are usually sent home to parents who have no experience or expertise to provide the typically intensive, often specialist, nursing, feeding and other physical care and assistance required by the child to survive. Some children may require extensive day and night intervention. Some die in their very early years. In 1998, 6 children involved in the Jack and Jill Children's Foundation's programme died in infancy.

All families in these circumstances find themselves isolated and without support. The absence of services and the insensitivity of existing rules on the Domiciliary Care Allowance and other issues reinforce the sense for these parents that they are alone and ignored.

The needs of each family in these circumstances are unique and may be variable from one period to another. Families often do not have the financial or other resources to provide the quantity and quality of care needed to ensure that their child is comfortable. Most families find the provision of round-the-clock intensive support and assistance to be exhausting. They value even a short planned break of a few hours. Most families have other children who have need of time and attention. Individual families may live in perpetual crisis, with parents and siblings under considerable, ongoing emotional and physical strain. Each year, some families live through the death of a child and need comfort and support.

## **MEMBERSHIP AND BOARD STRUCTURE**

The Jack and Jill Children's Foundation is not a membership-based organisation. At present, it provides services to 73 families. Its charity number is CHY: 231955. It has a voluntary board of 15 invited members, with rotation every 3 years. There are no upper or lower age limits for membership. The board has 4 meetings per annum.

The Jack and Jill Children's Foundation has a beneficiary committee, consisting of 5 members, which meets every 4-6 weeks. The committee members are selected on the basis of motivation and skills. The function of this committee is to examine requests for assistance from families and to oversee payments to families employing assistants.

## **INCOME AND EXPENDITURE**

The Jack and Jill Children's Foundation obtains no central government, health board or other statutory funding. It receives no EU or FAS CE funding. It is entirely reliant on charitable donations, mainly from private business. Fundraising methods include a golf classic in June, marathon participation (June) and sponsorships. Since its establishment, it has developed a trust fund with a view to medium and long-term support of increasing numbers of families with a child with severe developmental delay.

### *Expenditure*

The Jack and Jill Foundation currently spends about £100,000 per annum. Approximately half of this sum goes on staff costs, travel, telephone and office expenses. The other half goes directly to families. The foundation expects that its contributions to families will increase in the next number of years as more families are included, to approximately £200,000 - £250,000.

## **STAFF**

The Jack and Jill Children's Foundation employs a total of 3 staff. Two of these staff are full-time qualified, paediatric nurse specialists, called liaison nurses, who visit families throughout the country. One of these nurses was a new appointment in 1999. The third member of staff is a part-time office administrator. The foundation does not involve volunteers, other than at board or committee levels. It has no contact with the FAS CE programme.

### *Training, monitoring and evaluation procedures*

The Jack and Jill Children's Foundation has no formal induction or training programme, but assists staff to maintain and update skills. It has no written safety or complaints or internal reporting mechanisms. It considers that the calibre of its staff, the small size of the organisation and the direct, ongoing, informal contacts between staff and the chairperson ensure standards. The foundation expects that, as it grows, it will invoke increasingly formalised procedures. The Jack and Jill Children's Foundation has not undertaken an independent or an internal organisational or service user evaluation to date, as it has not been long enough in existence.

## **PREMISES**

The Jack and Jill Children's Foundation has a 1 room office with computer facilities.

## SERVICES

### INFORMATION SERVICES

The Jack and Jill Children's Foundation does not provide a formal information service to families, although the liaison nurses provide information as requested by parents. The foundation also assists in identifying qualified, paediatric nurses in the locality whom the family may contact in relation to potential employment.

#### *Publicity and fundraising information*

Most of the Jack and Jill Children's Foundation's fundraising is done through personal contact. The foundation wishes to raise public awareness about the paucity of services to under-4 year olds in this country and it seeks to raise public expectation of services. At present, it is planning a public media campaign to highlight the absence of services for very young children.

#### *Publications*

The Jack and Jill Children's Foundation promotes its activities through leaflets, brochures and a short video. It publishes an annual report and is about to start a newsletter. Lack of staff severely restricts the foundation in the development of publications.

#### *Research*

The Jack and Jill Children's Foundation is involved in research being undertaken at the Department of Developmental Studies, at University College Dublin (UCD). The foundation maintains links with organisations in Britain to keep abreast of medical and other developments.

### MEDICAL/NURSING/THERAPEUTIC SERVICES

#### *Liaison nurses*

Families are referred to the Jack and Jill Children's Foundation from maternity hospitals, children's hospitals, public health nurses and from parents themselves. The liaison nurse visits the family, provides an information and support service and evaluates the needs of each family and the ways in which the foundation might help. Each nurse provides an active service to about 40 families.

The nurses encourage and support families in sourcing family members and local individuals to provide the care required by the child. The Jack and Jill Children's Foundation then agrees to pay a monthly contribution to the parents to fund the work of that person. In some cases, due to the extent of the child's needs, the Jack and Jill Children's Foundation will source a suitably qualified nurse and will provide funds for the parents to employ this specialised person. Occasionally, the foundation also assists in the provision of necessary equipment. The Jack and Jill Children's Foundation has ongoing contacts with *A Nurse for Daniel*, a trust fund with similar aims and with the hospice movement.

## **SUPPORT SERVICES**

The foundation points to the complete absence of State-funded support services for families.

### *Respite services*

Holiday respite accommodation should be available to all of the families involved in the programme by 2000, through a network of B&Bs, family hotels and Barrettstown Castle, arranged through the Jack and Jill Children's Foundation. The foundation is currently in negotiations with Barrettstown Castle to assess the feasibility of using their facilities. Ideally,

the Jack and Jill Children's Foundation would like to obtain accommodation for 9 families per year, on a rotational basis. As the B&B and hotel breaks provide only limited 'respite' for parents, it is uncertain whether the foundation will proceed with these plans.

The Jack and Jill Children's Foundation initially considered that families would benefit from a respite centre, where babies with special needs could be cared for safely, while parents got a break. The experience to date is that when families are provided with even limited, ongoing home respite their quality of life improves and they do not seek residential respite.

### *Financial support*

The main service provided by the Jack and Jill Children's Foundation is financial assistance to families towards the purchase of home-based early intervention respite, often employing paediatric nurses. Families receive widely different levels of funds. Some families may receive approximately £30 per week. Others are in receipt of £800 per month. The foundation will sanction payment of between £3.50 -£6.50 per hour for most assistance, but will contribute £10.00 per hour to assist families to employ qualified paediatric specialist nurses. Families send in accounts on a regular basis which, when approved by the beneficiary committee are reimbursed, at the agreed rate, usually by return post. The Jack and Jill Children's Foundation also provides financial assistance with funeral expenses in extreme cases.

## **ADVOCACY SERVICES**

The Jack and Jill Children's Foundation engages in constructive dialogue with the Department of Health and Children and with individual politicians to promote its perspective. It has little direct contact with the health boards. It sees one of its core roles as the empowering of individual families to seek and obtain services locally. It supports individual families in obtaining the services they require.

## LEITRIM ASSOCIATION OF PEOPLE WITH DISABILITIES

Address: Credit Union buildings  
upper Main Street  
Mohill  
Co. Leitrim

Tel/fax: (078) 31845

Chairperson: Sr. Emmanuel  
FAS programme manager: Mary Boylan

### INTRODUCING THE LEITRIM ASSOCIATION OF PEOPLE WITH DISABILITIES

The Leitrim Association of People with Disabilities (LAPWD) was established in 1996 as a voluntary representative group for all people with physical and/or learning disabilities living in county Leitrim. Since its inception the LAPWD has relied on the FAS CE programme to provide personal assistants, and the consequent independent living opportunities, to people with significant physical disabilities in the Leitrim area. The LAPWD is extremely concerned that the FAS input might be discontinued and is uncertain of obtaining alternative sources for the personal assistant service. It is critical of the lack of statutory services available to members in Leitrim.

The main issue for the LAPWD is its need to secure ongoing core funding to continue and expand the PA service and to employ a support worker to begin to identify and address the wider needs of people with disabilities living in Leitrim.

### MEMBERSHIP AND BOARD STRUCTURE

Leitrim Association of People with Disabilities is a county organisation. Each person with a disability, their family members or care givers are welcome to become members of the association. In practice, the active membership fluctuates with the various undertakings of the association. It is a company limited by guarantee. The board comprises 11 members, most of whom are people with physical disabilities, with an annual rotation. Board meetings take place monthly.

### PERSONAL ASSISTANTS AND INDEPENDENT LIVING IN RURAL IRELAND

The PA service operated through the Leitrim Association of People with Disabilities shows how national schemes do not always take into account the different lifestyles and requirements of urban and rural living.

Lack of public or suitably priced private transport is a major problem in the operation of a PA service in rural areas. Most people who are eligible for employment as a PA in the current FAS scheme do not have their own transport and the scheme has no built-in travel costs. Travelling time may be extensive and is not remunerated. PA service at critical times (e.g. morning and evening) may be particularly difficult to arrange in rural areas.

PA services in both rural and urban areas have been greeted by people with disabilities as a genuine step forward in enabling them to live independent lives. As the schemes continue to expand, the expectations of people with physical disabilities will rise to include access to training and employment and to recreation facilities. Transport which is accessible to people with physical disabilities is a requirement for their inclusion in the rural community.

## **INCOME AND EXPENDITURE**

The total annual income, including FAS funding, is in the region of £100,000 per annum. Most of its funding to date has been obtained for specific educational or training projects. The FAS CE scheme accounts for £85,000 per annum approximately. The LAPWD has obtained funds from the North Western Health Board, the County Leitrim Partnership and the People in Need trust. It has also obtained funds from the Department of Family, Social and Community Affairs and the National Rehabilitation Board (NRB). It has received about £4,000 in charitable donations including £860 from local businesses and almost £2,000 from fundraising events. As a registered group member of the Co. Leitrim network of the Irish Council of People with Disabilities (ICPD), the LAPWD has access to a computer supplied by ICPD to equip each county network.

## **STAFF**

The LAPWD has no directly employed staff but operates a CE scheme with 16 CE workers. In all, 5 committee members act as volunteers in the organisation.

### *CE scheme*

LAPWD's CE scheme is vital to the continuation of the association. The mainstream employment placement rate for CE workers is 25%.

### *Training, monitoring and evaluation procedures*

CE workers follow a National University of Ireland (NUI), Maynooth certificate course in disability studies and personal assistant training. The LAPWD encourages all CE workers to complete the personal assistant training programme. In addition, it runs induction courses for new CE workers, with an emphasis on the philosophy of independent living. It has written safety and complaints procedures for the CE participants associated with the contractual and insurance requirements of the scheme. The LAPWD has not as yet undertaken any review of its performance since establishment but would be keen to do so if funds were available. In particular, it would value external assistance in drawing up a plan of action for the next 3-5 years.

## **PREMISES**

The LAPWD has an office in the Credit Union Building in Mohill at a nominal rent and an outreach office in Manorhamilton. These have partial disabled access and a drop-in facility but no meeting rooms. The association has computers at both locations.

## **SERVICES**

### **INFORMATION SERVICES**

The LAPWD operates a limited telephone information service to people with disabilities and their families. Information is provided on a wide range of topics with onward referral to specialist agencies in the Leitrim area. The LAPWD has a brochure about its activities.

Once a month the LAPWD contributes to a column in the *Leitrim Observer* newspaper. This column entitled *This Ability* covers the activities of the group, gives publicity for forthcoming events and raises disability awareness.

#### **EDUCATION SERVICES**

The LAPWD has organised a number of educational courses for members with the financial assistance of the Leitrim Partnership. It has run a computer course for 10 participants to develop basic computer literacy. It has also run a personal development course for 15 people, including members with disabilities, caregivers, volunteers and PAs. The LAPWD has plans to run an advanced computer course with funds from the People in Need trust.

#### **SUPPORT SERVICES**

The LAPWD provides a support service for people who have been diagnosed as having early multiple sclerosis. It runs a support group which meets frequently, but irregularly. The LAPWD has a support worker through the Job Initiative programme, sponsored by County Leitrim Partnership and funded by FAS. The support worker undertakes office-based and outreach activities with people with disabilities living in the county. The LAPWD has recently appointed a development officer with funding obtained from the EU special support programme for Peace and Reconciliation. Part of this person's brief is to set up additional support groups, e.g. for people with rheumatoid arthritis and a carers' support group.

#### **INDEPENDENCE SERVICES**

The LAPWD operates a personal assistant (PA) service through a FAS CE scheme. In total, 16 CE workers are employed, including 1 supervisor and 1 administrator. In all, 14 CE workers act as PAs to 13 people with physical disabilities. The service is limited to approximately 20 hours per week per person (40 hours for 1 of the participants only). People in receipt of the service are generally pleased with it, with some participants seeking extra hours of PA service and some eager to use it to expand their working or leisure interests. The LAPWD does not keep a waiting list as it cannot give commitments to expand the service.

#### *Plans for independence services*

The LAPWD has made a successful submission to the Peace and Reconciliation programme with a view to obtaining funds for the establishment of a member's cooperative, which in time would lead to employment opportunities for people with disabilities in the Leitrim and cross-border areas.

### **ADVOCACY SERVICES**

The LAPWD lobbies politicians and health board administrators to obtain improved services for people with disabilities in the Leitrim area. It has run a number of advocacy training courses for members. It enabled 23 people (with physical disabilities, parents of children with learning disabilities, volunteers and PAs) to attend an introductory course in community development in relation to disability; certificated by NUI; Maynooth during 97/98. This course was sponsored by the Leitrim Partnership (£4,000). With DFI assistance, the LAPWD has undertaken a millennium project to investigate the possibilities of co-ordinating the work of voluntary groups in the Leitrim area.



# MS IRELAND

## MULTIPLE SCLEROSIS SOCIETY OF IRELAND

Address: MS Ireland  
Royal Hospital  
Donnybrook  
Bloomfield Avenue  
Morehampton Road  
Dublin 4

Tel: (01) 2694599  
Fax: (01) 2693746  
Free phone: 1850 233233  
(Mon-Fri 10.00 am - 5.00 pm)

E-mail: [mssoi@iol.ie](mailto:mssoi@iol.ie)  
Website: [www.ms-society.ie](http://www.ms-society.ie)

Chief executive: Michael Dineen

Also: MS Care Centre  
65 Bushy Park Road  
Rathgar  
Dublin 6

Tel: (01) 4906234  
Fax: (01) 4906724

E-mail: [mssc@oceanfree.net](mailto:mssc@oceanfree.net)

Centre manager: Patricia McLarty

### MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is a condition of the brain and spinal cord. It involves loss of the covering of the nerve fibres (the myelin) and damage to the nerves themselves. It is not a mental illness and is not contagious. MS is one of the most common neurological problems of young adults, affecting people between the ages of 15-60 years. The highest incidence occurs between the ages of 20-40 years.

The condition affects many parts of the central nervous system and so gives rise to variable symptoms which may include problems with vision, speech, sensation or movement. For individuals, the variability of the symptoms can give rise to drastic changes in their lifestyle, their ability to work, their family life and emotional well-being. For some people symptoms are mild, for others they may be severe. Most people with MS experience periods of remission when the acute symptoms subside and they can continue life as before, possibly with some extra support. Each person's prognosis is uncertain and this causes additional strain to them and to their families.

At present, there is no cure for MS. The condition can be managed with a good diet, adequate rest and appropriate treatment, e.g. physiotherapy to relieve muscle tightening. Some people are helped by drug therapy. Most people with MS benefit from counselling to help them live and manage their condition. Family members may also need assistance in understanding and accepting multiple sclerosis.

### INTRODUCING MS IRELAND

MS Ireland is the Multiple Sclerosis Society of Ireland. It was established in 1963 and has developed nationally, providing information and support to people with multiple sclerosis, their families and caregivers. It also funds research into the causes and best management of multiple sclerosis. It recently amalgamated with the MS Care Centre as a company limited by guarantee. The MS Care Centre opened in 1989. It is a national, residential respite service providing short-term residential respite and therapy services to people with multiple sclerosis and other neurological disabilities. The service has developed in the past decade to provide quality respite care and therapy.

MS Ireland has been instrumental in developing public awareness of multiple sclerosis. It has highlighted the absence and inadequacy of existing health service and social welfare responses to people with the condition, in particular the absence of suitable respite services and the inadequacy of housing grants. It is critical of the lack, and uncoordinated nature, of community services nationally, particularly the lack of adult social work services. It campaigns for improved services nationally. It provides a range of services through its national and regional network. It is also critical of the problems faced by members resulting from the lack of transport and of employment opportunities. At an organisational level, it points to problems in recruiting and retaining volunteers and to the insufficiency of State funding for professional non-governmental services.

MS Ireland points to the continuing demand for its limited respite places. The MS Care Centre has difficulty in recruiting and retaining suitable staff. It acknowledges its high reliance on the CE scheme and is concerned about the implications of this, both now and in the future.

#### **MEMBERSHIP AND BOARD STRUCTURE**

MS Ireland has a total membership of 3,500. This includes 1,000 in the Dublin area and a regional membership of 2,500. The society has 37 voluntary branches, run entirely by volunteers. Services are provided to nonmembers.

MS Ireland is a company limited by guarantee. Its charity number is CHY: 5365. The national executive committee (NEC) of MS Ireland consists of 17 members, including 13 people with multiple sclerosis. The rotation is every 3 years and the committee meets 6 times per annum. The NEC is supported and monitored by the national representative council (NRC), an elected body representing the branches of the society and the membership generally. The MS Care Centre's activities are overseen by an appointed voluntary management committee. The centre has a manager in charge of day-to-day operation. MS Ireland is a member of the International Federation of Multiple Sclerosis Societies and the European MS Platform.

#### **INCOME AND EXPENDITURE**

MS Ireland's turnover is about £2m. per annum. The society obtains no EU funds. It has received variable funding from State sources, nationally and regionally. The society's participation in FAS CE schemes is valued at £250,000, about half of which relates to the MS Care Centre. It obtains £450,000 from private charitable donations. MS Ireland raises £1.2m. annually, more than 50% of its annual budget, through methods including the sale of Christmas cards, a national *Readathon* in November/December, international walks in May and November and a national *Pen day* in April/May. The cost of raising this sum is about £420,000 per annum.

#### *Expenditure*

MS Ireland spends about £932,000 on directly paid staff salaries and wages. The society covers a shortfall of approximately £200,000 in the accounts of the MS Care Centre, as the core grant from the Eastern Health Board (£240,000) and additional subscriptions do not cover the full costs of the centre. MS Ireland spends approximately £120,000 a year on the premises and operational costs of its regional staff network and about £100,000 on the

administration of that network. It spends about £100,000 a year to support its branches. The volunteer programme is costed at £80,000+ per annum. A sum of £100,000 per annum is spent on information, training, seminars and public meetings. It has an annual emergency fund of about £80,000. Setting up and maintaining its website cost about £30,000. It spent £30,000 on legal fees in association with the amalgamation of its main structures.

#### **STAFF**

MS Ireland employs a total of 45 staff members. They include 3 management and 7 administrative staff, some of whom provide an information service to the public and some of whom are employed in the MS Care Centre. MS Ireland employs 3 fundraising secretaries. All administrative and field staff are trained and qualified for their roles. MS Ireland has about 200 volunteers.

#### *CE scheme*

MS Ireland uses its CE participation to provide rural support for regional branches and as a backup for the national MS Care Centre in Dublin. The placement rate for CE workers has improved rapidly in the recent past, as a result of the economic upturn. The MS Care Centre is heavily reliant on CE workers. The scheme at the centre provides 2/3 administrative staff, all laundry and gardening/maintenance and 1 of 5 care workers. The success rate of placement of CE workers in mainstream employment from the care centre is 70%.

#### *Training, monitoring and evaluation procedures*

MS Ireland has induction programmes for staff and CE workers. At present, it does not operate any specific accredited training programmes, but it sees value in doing so. It uses the services of specialist agencies. It organises educational seminars for staff, CE workers and volunteers. It also runs regular support meetings for all staff and provides financial support for agreed external training. It uses the CE materials' grant to assist in training the CE workers. MS Ireland has written safety, complaints, internal reporting mechanisms. It is currently drawing up revised safety and monitoring procedures which will be implemented through all parts of the society's activities. MS Ireland undertook an independent organisational evaluation in 1989 and an internal evaluation in 1992-4. All of the MS Ireland services are continually evaluated in terms of priority, need and cost. The MS Care Centre was independently evaluated in 1994 and 1999.

#### **PREMISES**

MS Ireland has a range of premises. These include the national office, 8 regional offices and the MS Care Centre. The society is computerised and has disabled access and meeting facilities in most of its locations.

The MS Care Centre has 8 *en suite* bedrooms, 2 communal living areas, a library, dining room, jacuzzi room, therapy room, support rooms, kitchen, laundry and offices. All bedrooms are fully accessible and have ramps for garden access. The centre has 4 computers, internet access and an e-mail facility. 2 meeting rooms are available. The centre is set in attractive grounds.

## SERVICES

### INFORMATION SERVICES

MS Ireland provides an information service about multiple sclerosis and about social welfare and other entitlements to members and their families. It operates a free-phone number (1850 233233) from 10.00 am to 5.00 pm, weekdays. This line is called *MS Contact*. It gives information on entitlements, literature on MS, research, counselling, physiotherapy, diet, home helps, house conversion and other topics. The society has a website, [www.ms-society.ie](http://www.ms-society.ie) which details its national and regional services and describes the national MS Care Centre.

The society also employs 10 regional community workers (see separate page) who provide information services and arrange meetings and seminars in the regions. Each of the regional community workers provides information to new and established members and gives talks and presentations for various groups, including schools, on request.

### *Media campaigns*

MS Ireland runs media campaigns in conjunction with fundraising events. MS Ireland's *Readathon*, a fundraising event, involves 650 schools and 25,000 pupils.

### *Publications*

The society produces a range of leaflets and other literature about multiple sclerosis and issues of concern to members and their families. It produces a quarterly newsletter *MS News* and publishes an annual report.

### *Research*

MS Ireland spends £100,000 per annum on research in Irish universities. This research fund is managed by a research committee comprising specialists in the field of multiple sclerosis research. Applications come from laboratory, clinical, epidemiological and psycho/sociological projects. MS Ireland plans to double its expenditure on research in the next period.

### *Plans for information services*

The society is preparing a video for use in schools and for its regional network.

### MEDICAL/NURSING/THERAPEUTIC SERVICES

#### *National multi disciplinary MS clinic*

MS Ireland was actively involved in the establishment of, and continues to be associated with, the multi-disciplinary clinic at Beaumont Hospital, Dublin 9, which aims to provide a holistic medical and surgical response to people with MS. Staff includes a consultant neurologist, a genitourinary surgeon, an occupational therapist, a medical social worker, a physiotherapist with expertise in urinary incontinence, a dedicated liaison nurse and a community worker employed by MS Ireland. People attending the clinic have same-day access to social services, speech and language therapy and dietetics.

#### *Care and nursing services*

The MS Care Centre has a team of qualified care workers and a 24-hour qualified nursing service.

### *Therapy services*

For respite residents, the MS Care Centre provides physiotherapy, occupational therapy, massage, art therapy, yoga and a qualified counselling service. Reflexology and chiropody are available at extra cost. MS Ireland organises varying amounts of physiotherapy and reflexology on a sessional basis through the branch network.

### **SUPPORT SERVICES**

MS Ireland operates a national free-phone help line. Regional offices also respond to telephone requests for support. The regional community worker network provides personal and family support services. The branch network throughout the country provides an extensive range of support services including social outlets, meetings, support groups for people with MS and their families or caregivers.

### *Counselling services*

The society provides sessional counselling, free at the point of delivery, through a national network of 24 sessionally-paid, trained, professional counsellors. Regional branches provide peer counselling and opportunities to train in counselling and respond to requests for professional counselling. The MS Care Centre provides personal, group, family, marital and child counselling on request from residents.

### *Respite services*

MS Ireland operates the 8-bedroom MS Care Centre in Rathgar, in Dublin 6. In total, 8 individuals per week obtain a residential respite service, for a maximum of a 2-week stay per year. Services are provided to anyone who satisfies the admission criteria. The cost of the stay is waived for people who cannot afford it and who do not have medical insurance or eligibility through the medical card system.

The society also avails of respite services offered by other agencies in regional areas. The society plans to extend the Rathgar centre and also to develop a major respite centre in the south of the country.

### *Visiting services*

An important aspect of the work of the regional branches is home visiting and support by volunteers.

### *Financial support*

MS Ireland and its constituent branches provide occasional financial support to families in distress or for the purchase of necessary equipment.

### *Equipment purchase or loan*

Residents at the MS Care Centre may try, use or be assessed for equipment and very short-term loans can be arranged.

## **MS Ireland REGIONAL COMMUNITY WORKERS AND OFFICES**

### **Eastern Health Board**

**South Dublin/Wicklow**  
Jennifer Reilly  
MS regional office  
Royal Hospital  
Donnybrook  
Dublin 4  
Tel: (01) 2694599

### **West Dublin/Kildare**

Helen O'Connor  
MS regional office  
Royal Hospital  
Donnybrook  
Dublin 4  
Tel: (01) 2694599

### **Midland Health Board**

Mary Leonard  
MS regional office  
Athlone  
Co. Westmeath

### **Mid Western Health Board**

Gretta Allen  
MS regional office  
AIB Building  
Dublin Road  
Castletroy  
Limerick  
Tel: (061) 335565

### **North Eastern Health Board**

Kevin Curran  
c/o NEHB  
Old Rooskey office  
Monaghan Town  
Tel: (047) -81355

### **North Western Health Board**

Josephine Tinneney,  
MS Regional office,  
30 Academy Court  
Pearse Street  
Letterkenny  
Co. Donegal  
(074) 25017  
E-mail: msinwregof@tinet.ie

### **South Eastern Health Board**

Katie Hourigan  
MS regional office  
Nuncio Road  
Waterford Road  
Kilkenny  
Tel/fax: (056) 51522

### **Southern Health Board**

Michael Shemeld  
MS regional office  
North Quay House  
Pope's Quay  
Cork  
Tel: (021) 300001  
E-mail: msirelandgalway@tinet.ie

### **Western Health Board**

Aidan Larkin  
MS regional office  
35-37 Dominick Street  
Galway  
Tel: (091) 562737

## **RECREATION SERVICES**

MS Ireland, through its branches, organises social outlets, monthly meetings, summer outings and Christmas parties. Some branches organise swimming for members. Holiday visits to Trabolgan, Lourdes and Knock are organised. At the MS Care Centre, in-house entertainment is provided at least once a week by professional or semi-professional entertainers. Centre transport is available for shopping and day trips etc.

## **INDEPENDENCE SERVICES**

The MS Care Centre's ethos is to provide disability management advice and to promote individual independence. Regional officers and branches run personal development courses.

### **ADVOCACY SERVICES**

MS Ireland is the national non-governmental representative body for people whose lives are affected by multiple sclerosis. The society campaigns for improved conditions and access to services and has extensive contacts with government departments, health boards, local authorities and other regional agencies. It points to its ongoing campaign to improve the grant-aid available to people with disabilities to modify their homes. This is currently set at a maximum of £14,000 and, at best, covers merely half the cost of extensive external and internal rearrangement. MS Ireland argues that, for people on fixed or low incomes, the paucity of local authority aid means that they are unable to modify their homes to improve their quality of life. The MS Care Centre has ongoing contact with the Eastern Health Board in relation to service provision and funding.

The society actively encourages members to act as self-advocates and stresses that its services do not create dependency but foster self-reliance, personal development and coping skills. Regional community workers act as advocates for members.

# MUSCULAR DYSTROPHY IRELAND (MDI)

Address: Carmichael Centre  
north Brunswick Street  
Dublin 7

Tel: (01) 8721501  
Free phone: 1800 245 300  
Fax: (01) 8724482

E-mail: [info@mdi.ie](mailto:info@mdi.ie)  
Website: [www.mdi.ie](http://www.mdi.ie)

Director: Catherine Hickey  
Information officer: Helen O'Brien

## MUSCULAR DYSTROPHY

Muscular dystrophy is a collective term for a wide range of neuromuscular disorders characterised by the progressive degeneration and weakening of muscles. It affects both adults and children. All forms of muscular dystrophy are hereditary, with the genetic defect transmitted by one parent in some forms, and both parents in others. However, there are many cases of muscular dystrophy in families with no known history of the condition, which are caused by spontaneous mutations.

## INTRODUCING MUSCULAR DYSTROPHY IRELAND (MDI)

Muscular Dystrophy Ireland (MDI) was founded in 1972 to provide care and support to people with neuromuscular conditions and their families and to fund medical research. MDI is particularly concerned about individuals with neuromuscular conditions who remain in a hospital or are effectively housebound because of the lack of back-up in the community.

In the past 10 years, MDI has developed specialised family support, respite and holiday services and projects. MDI faces significant problems in ensuring services for its members. It has no core funding for regional staff, for its national administrator position or for staff training. It lacks adequate resourcing for its youth service. It has ongoing difficulties in recruiting and retaining suitable care work personnel and in sourcing appropriate training in lifting and handling.

## MEMBERSHIP AND BOARD STRUCTURE

MDI has a national membership of 450 families with 5 regional branches (Dublin, Cork, Galway, Donegal and Dundalk). Services are provided to nonmembers. MDI seeks to be flexible in providing assistance to families and individuals.

MDI is a company limited by guarantee. Its charity number is CHY: 6489. The board of management (the council) comprises 24 members including 4 executive officers and 20 ordinary council members. Membership rotation is annual. The council meets 4 times per year.

## INCOME AND EXPENDITURE

MDI obtains £20,000 per year through European Union (EU) funding of employment programmes. State funding of the organisation amounts to £150,000 a year. This sum includes funding from all but one of the health boards. MDI obtains an annual grant of £75,000 from



the Eastern Health Board and £30,000 towards a joint project with the Irish Association for Spina Bifida and Hydrocephalus (IASBH) Dublin branch, employing a job-share family support worker for both organisations. MDI obtains an annual grant of £15,000 from the Eastern Health Board from the respite fund (national lottery source). The Midland Health Board provides no funding to MDI. The Mid Western Health Board gave a total of £2,000 in 1999 for respite provision in the region in that year. The North Eastern Health Board gives a grant of £3,000 towards MDI services in the region. The North Western Health gives £3,000 towards the employment of a part-time family support worker in the region. The South Eastern Health Board provided £2,500 towards MDI services in the region in 1999. The Southern Health Board provided £1,000 to MDI for respite provision in 1999. The Western Health Board provided £1,000 towards the MDI family support worker in Galway city in 1999. Bequests, charitable and corporate donations and fundraising income provide approximately £50,000 per year.

Eastern Health Board	£90,000
Midland Health Board	NIL
Mid Western Health Board	£2,000
North Eastern Health board	£3,000
North Western Health Board	£3,000
South Eastern Health Board	£2,500
Southern Health Board	£1,000
Western Health Board	£1,000

**Expenditure**

MDI spends about £300,000 per annum. Total staff wage costs per annum come to £150,000. MDI's national respite service costs £30,000 per annum. The information service (including public relations) costs £20,000. Youth group services cost about £10,000. MDI has a philosophy of keeping secretarial/administrative costs to an absolute minimum. At present, the cost of the administration of the MDI service as a whole is approximately £35,000. MDI operates an extensive regional service system. Approximate costs for each region for 1999 are presented in the box across.

Eastern Health Board	£107,000
Midland Health Board	£3,000
Mid Western Health Board	£3,000
North Eastern Health Board	£20,000 +
North Western Health Board	£10,000 +
South Eastern Health Board	£10,000+
Southern Health Board	£20,000+
Western Health Board	£20,000+

**STAFF**

MDI staff consists of approximately 15, many of whom work part-time. Core staff include the director, 5 family support workers, 2 sessional counsellors, 1 course coordinator, 1 information / PR officer, 1 youth worker, 1 care coordinator and 3 part-time staff in the secretariat. MDI also has a team of 15-18 careworkers who work directly with families and has a number of volunteers.

**CE scheme**

MDI has no direct involvement with the FAS CE programme, but utilises the CE scheme in operation in the Carmichael Centre. In the Cork area, MDI participates in a joint CE scheme with Abode and the Special Olympics and has 5 workers. MDI has an involvement in the FAS Job Training Scheme.

### *Training, monitoring and evaluation procedures*

MDI does not operate any accredited training programmes but pays for external training for staff. The organisation sees value in developing accredited training programmes for new staff/CE participants in areas of care. MDI has in-house induction and ongoing training programmes for staff and volunteers. MDI has written safety procedures and internal reporting mechanisms. MDI undertook independent organisational evaluations in 1989 & 1995 and an internal administrative organisational evaluation in 1999. It plans to evaluate the family support service in 2000.

### **PREMISES**

MDI has 2 offices in the Carmichael Centre in Dublin's north inner city with full disabled access, computerisation, drop-in facilities and the use of meeting rooms. It rents an office in Cork and in Galway.

## **SERVICES**

### **INFORMATION SERVICES**

#### *To members/families*

The MDI information service is the organisation's first source of assistance for people affected by a neuromuscular condition. It provides information about neuromuscular conditions and other subjects such as benefits, holidays, transport, support groups, genetics etc. Enquiries are received by letter or by telephone from people who have neuromuscular conditions, their families and friends, professionals such as occupational therapists, public health nurses, general practitioners and from members of other organisations. MDI operates a freephone 1800 245 300 and has a website: [www.mdi.ie](http://www.mdi.ie)

#### *Public awareness*

Public awareness and public relations are dealt with by a full time information/public relations officer. The family support workers will speak with classes (at primary, secondary or third level) about the issues affecting people with neuromuscular conditions. MDI engages the services of Heneghan Public Relations to assist it in developing public awareness through an awareness week, a redesign of the logo, increasing media exposure for MDI and event management.

#### *Publications*

Many free and useful leaflets and booklets about neuromuscular conditions and all issues which surround them are available at the office. MDI publishes a newsletter 4 times a year called *MDI Magazine*. It is produced by staff at the Cork office. The magazine contains up-to-date research information, reports on MDI activities, fundraising events etc., and lists forthcoming social events. The organisation does not produce an annual report.

#### *Research*

The information officer gathers and disseminates information on the neuromuscular conditions and is at present developing a data bank of scientific and medical research information for members and healthcare professionals and keeps abreast of all developments in research

throughout Europe and America. In 1999, MDI presented a report on the impact of muscular dystrophy on 93 families throughout the country. MDI has a research panel and committee which provide funds to suitable external research projects.

#### **SUPPORT SERVICES**

MDI's support services are provided by 5 family support workers who visit individuals and families. It also retains the services of a specialist, qualified counsellor on a sessional basis.

#### *Family support services*

The MDI family support worker visits members in their own homes and identifies, evaluates and advises on the problems that arise with neuromuscular conditions. Through home visits, the family support worker develops a relationship with the families and spends time with them so that they can understand the information which has been provided.

The family support worker also:

- helps parents to cope with the needs of the unaffected children as well as those of their affected child or children,
- provides services to the relatives of the affected members who, due to the hereditary nature of the condition, may be at risk of having affected children and who may be in need of advice or support,
- provides the relevant information and support for the adult who has just been diagnosed as having a neuromuscular condition and will also provide ongoing counselling and practical support for these adults and their families.
- liaises with other professionals - such as public health nurses, social workers, physiotherapists or occupational therapists in the various health boards,
- is available to speak with teachers on a one-to-one basis (if a parent or teacher so wishes).

#### *Support networks*

MDI's women's support group was set up in 1989 by mothers whose sons had Duchenne muscular dystrophy. Over the years, mothers whose children have a variety of neuromuscular conditions have joined in the group.

#### **Family support workers**

Muscular Dystrophy Ireland currently employs five family support workers to provide a nationwide service to members.

Mary Borton covers the Eastern Health Board region - Dublin, Kildare and Wicklow. Tel:- 1800-245-300.

Caroline Moran covers the Western, North Western and Midland Health Board regions - Galway, Mayo, Roscommon, Westmeath, Offaly, Longford, Sligo, Leitrim, and Donegal. Tel:- 091-773919.

Catherine Jones covers the North Eastern Health Board region - Cavan, Monaghan, Louth and Meath. Tel:- 01-8258142.

Mary O' Sullivan covers the Southern and Mid Western Health Board regions - Cork, Kerry, Clare, Limerick and Tipperary. Tel:- 021-551196 / 551197.

Marie C. Kealy covers the South Eastern Health Board - Carlow, Wexford, Kilkenny, Laois and Waterford. Tel:- 1800-245-300.

### *Counselling services*

In early 1998, MDI commenced a therapeutic counselling service to the members of MDI. This provides an opportunity for members to come to the Carmichael Centre and work through any issues which may be preventing them from leading a full life and moving forward. The service assists people with muscular dystrophy, parents, couples and bereaved family members.

### *Respite services*

Muscular Dystrophy Ireland's respite care service was established in 1994, with the appointment of a respite care worker and initial funding from the (then) Department of Social Welfare respite care fund. The MDI respite service assists families in coping with the care of a person affected with a severe neuromuscular condition. The organisation has developed a series of highly flexible respite responses to cope with the range of needs of members.

The MDI respite service in the greater Dublin area, Cork and Galway is as follows: -

- Nighttime home-care service - for members who require care during the night, to give the parent/carer a break, for one or two nights per week. The primary users of this service are parents and carers of boys with Duchenne muscular dystrophy.
- Care assistance for adults with neuromuscular conditions - as required by the adult member (e.g. 6-12 hours per week).
- Occasional weekend breaks for parents/carers. Care can be provided in the home for the weekend.
- Care assistance for a period of two to three weeks in the family home, in the event of hospitalisation of a parent or carer of a person affected by muscular dystrophy. This service is usually operated on a planned basis and bookings are taken in advance.
- Occasional overnight stays where the parent/carer may need to be away from the home for an appointment or meeting.

MDI also provides a respite service outside of the above-mentioned areas: -

- Care assistance in the family home can be provided on a planned basis - periodically.
- A nighttime service can be arranged to assist with turning etc. one or two nights a week.

### *Financial support*

MDI assists in payment for the services of a private home care agency when necessary. Also, the services of a nursing agency are obtained when it is deemed that special care is required.

### *Equipment purchase or loan*

MDI has equipment such as electric wheelchairs, beds, cushions and computers and these items are available to members on long-term loans.

## **RECREATION SERVICES**

The MDI youth group meets weekly in Dublin on a Saturday. The youth group currently only caters for members from Dublin, Kildare and Wicklow. Weekly art, music dance and drama classes are also provided for the young members.

### *Holidays*

MDI offers a range of holiday programmes to members nationwide. In 1999, 60 young people and their helpers enjoyed holidays both in Ireland and elsewhere.

### **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

#### *Training*

MDI operates a European Computer Driving Licence (ECDL) computer training course. This course was designed to provide participants with the information technology (IT) and communications skills needed to enable them to progress to employment, further training or education. MDI plans to further expand its IT programmes.

### **INDEPENDENCE SERVICES**

#### *PA services*

In all, 10 people with muscular dystrophy use the IWA Eastern Health Board-funded PA scheme. MDI provides a back-up service to persons with muscular dystrophy using a personal assistance service. In Galway, members of MDI have a PA service through CIL, using a CE scheme.

### **ADVOCACY SERVICES**

MDI is the national non-governmental, representative body for people with muscular dystrophy and their families. It seeks active and positive dialogue with all State agencies involved in health service provision and has ongoing contact with politicians, government departments and health boards. MDI policy includes a strong commitment to the rights of all people with disabilities. The organisation has been active in assisting the development of PA schemes and supports the Center for Independent Living (CIL) in its demands for an Independent Living fund. MDI looks to DFI as a significant advocacy group. MDI seeks to promote independence and opportunities for all members.

# **NATIONAL ASSOCIATION FOR DEAF PEOPLE (NAD)**

Address: 35 North Frederick Street  
Dublin 1

Tel: (01) 8728300

Fax: (01) 8723816

E-mail: [nad@iol.ie](mailto:nad@iol.ie)

Website: [www.iol.ie/~nad/](http://www.iol.ie/~nad/)

CEO: Niall Keane

## **INTRODUCING THE NATIONAL ASSOCIATION FOR DEAF PEOPLE (NAD)**

The National Association for Deaf People (NAD) is the largest voluntary organisation providing services to hearing-impaired people and parents of deaf children. It has a network of resource centres nationally.

## **PREMISES**

The NAD operates from offices in Dublin 1 which include a Citizen's Information Centre (CIC) which is open-plan with 2 meeting rooms, a coffee dock, a library. Deaftech Resource Centre is also in the building.

## **SERVICES**

### **INFORMATION SERVICES**

The NAD headquarters at north Frederick Street, Dublin 1 houses a Citizen's Information Centre (CIC). This project is supported by the National Social Services Board (NSSB) and was opened in 1998. It focuses on a one-stop-shop provision of information to people with sensory disabilities. The topics of information include rights and entitlements, disability information, social welfare and health services, and equipment and information about deafness. A professional and comprehensive information system in sign language is provided as part of the CIC service. More than 6,000 clients have used the CIC. The office is open 9.00 am to 5.00 pm, Monday to Friday (including lunch hours). Clients may make appointments with an information officer on request.

### *Library services*

The NAD has a library of leaflets and reference books on deafness and NSSB files on computer or in paper format.

## SUPPORT SERVICES

The NAD has a range of family support services. These include counselling and social work.

### NATIONAL ASSOCIATION FOR DEAF PEOPLE SUPPORT SERVICES

Contact the association by phone, minicom or letter for an appointment. Call in to the main office any Wednesday 10.00 am -12.30 pm..

#### *Family support services/counselling services*

This is available for all deaf and hard of hearing people and their families. The service is strictly confidential and is offered through the communication of the client's choice, i.e. Irish Sign Language, lip-reading or speech. The service is

staffed by professional social workers and family counsellors. The aim of the service is to enable deaf people to participate fully in all areas of life and to support families in developing good relationships and communication.

#### *Parental support network/peer support*

The family support service has a network of trained parent volunteers who provide peer support to parents of deaf children

#### *Family interaction programme*

This is a specialised programme which assists parents to support their children's development. Sessions usually take place in the home and video recording is used to give parents information in a clear and specific way.

#### *Interpreter/assistance service*

The CIC at north Frederick Street provides a range of support and enabling services to users. For example, staff will make calls on clients' behalf and will provide a communication support by accompanying people who may require a signer present when doing business with other agencies. These services include free use of minicom and fax machines.

#### *Equipment purchase or loan*

The NAD operates a national resource centre as a commercial division called Deaftech. This sources, advises on the suitability of and supplies a wide range of nonmedical technical appliances. It can also assist educationalists, employers and staff concerned with access and safety for people who are hearing impaired. Among the ranges of products are hearing aid boosters and other amplifiers for TV and radio listening, video caption readers, telephone amplifiers, flashing door bells and flashing smoke alarms. It also provides a repair service for some of these aids. It supplies Royal National Institute of the Deaf (RNID) tapes to aid relaxation for people with tinnitus (ringing in the ears).

## ADVOCACY SERVICES

NAD staff members will act as advocates for clients in seeking entitlements, in obtaining information and services.

# NATIONAL COUNCIL FOR THE BLIND OF IRELAND (NCBI)

Address: Whitworth Road  
Drumcondra  
Dublin 9

Tel: (01) 8307033  
Fax: (01) 8307787

E-mail: [info@ncbi.ie](mailto:info@ncbi.ie)  
Website: [www.ncbi.ie](http://www.ncbi.ie)

Chief executive: Des Kenny

## INTRODUCING NATIONAL COUNCIL FOR THE BLIND OF IRELAND

The NCBI was founded in 1931. It provides services nationally for people who experience problems with their eyesight. About 1,000 people every year use the services of the NCBI. Approximately 22% of all people using NCBI's services are completely blind. The remaining 78% have varying degrees of usable, residual vision. The NCBI is currently finalising a 3-year strategy for 2000-2002 which will seek to reflect the wishes of blind and visually impaired people nationally and to focus on specific groups including children, newly registered visually impaired people and older people who are blind or visually impaired.

## MEMBERSHIP AND BOARD STRUCTURE

The NCBI does not yet create its user-base into a membership as such. The NCBI keeps a register of its service users and potential users on a blind person's register. A person can obtain NCBI services without being on this register. The NCBI will remove the name of any person from the register, on that person's request. To obtain NCBI services a person must have a visual problem. About 7,000 people are eligible to obtain NCBI services in Ireland.

The NCBI has county branches, originally set up to raise funds for the employment of the local, paid NCBI worker. This role has decreased in importance, due to alterations in central and regional financing. Local branch funds are now directed to local recreational and leisure activities for visually impaired people in the area. The NCBI has set targets to facilitate the passing of control of the county branches to visually impaired people.

The NCBI is a company limited by guarantee. Its charity number is CHY: 6246. The board has a membership of 18. At least one-third of its membership must be individuals who are registered as visually impaired or are the parents of visually impaired children. Board membership rotates every 3 years, with one-third of the membership retiring annually. The

### VISUAL IMPAIRMENT

The word "blind" is often used to refer to people with a visual impairment. However, research shows that more than 80% of people registered as blind have usable residual vision. For some people, age brings significant deterioration of sight.

In order to obtain statutory benefits a person must have defined levels of maximum vision. Many people with visual impairment are assisted by technological aids which, for example, enlarge print or convert print to speech or braille, or vice versa.

Blind or visually impaired people can do a wide variety of different work. The range of employment options for these people has increased substantially with the advent of computerisation and information technology.



board meets 10 times a year. The board is served by a management committee which meets with the chief executive every 2-3 weeks to deal with all matters relating to policy and major expenditure, and to ensure that the board of directors receives adequate information to assist their decision-making and policy management roles.

#### **INCOME AND EXPENDITURE**

The NCBI has an income of approximately £3m per annum. The council obtains funds from State sources, specifically the health boards. In 1999, the NCBI obtained £1,635,741 from the health boards. It also received £208,722 in EU funding in that year. Its CE participation is worth approximately £256,000 per annum. Sales of services and appliances brought in £694,079, while the gross fundraising income from all sources was £696,979. The NCBI also obtained a grant of £15,000 from the National Social Service Board (NSSB). The NCBI showed a deficit of £180,000 in the 1999 accounts.

#### *Fundraising*

The NCBI has a number of innovative fundraising schemes including its *Millennium Tree of Light* project, in association with Aer Rianta and donor companies. Other charity fundraising ventures include its *Blazing Saddles* national and international cycling events. It has also organised a ski challenge in the Austrian Tyrol and hiking charity treks in the Himalayas and Thailand. It obtains funds from sales from its extensive catalogue of aids and appliances for people with visual impairment.

#### **STAFF**

The NCBI has a staff structure which includes the CEO and departments dealing with public relations, fundraising, planning and development, finance/account and payroll, technology, community resources, EU-funded projects, a library, a shop, a low vision clinic, personnel, an access advisor, a buildings and maintenance officer and a FAS supervisor. Community resource workers provide a range of local services.

#### *CE scheme*

The NCBI participates in 2 separate CE schemes. In total, 15 workers and a supervisor work in the council's charity shops. At Whitworth Road, 20 CE workers and supervisor are employed. These staff undertake a wide range of duties including reading recording scanning into digital format, providing an express and education reading service, processing 4-track tapes and assisting in the library.

The NCBI expresses general satisfaction with the CE schemes, while acknowledging its inherent limitations. The council places an emphasis on training as a means of personal development for all CE workers. Between 50-60% of CE workers with the NCBI have gone on to mainstream employment.

#### *Volunteers*

The NCBI has a national network of volunteers. These people undertake fundraising, visiting of blind and visually impaired people in their neighbourhoods and support of local staff members. The NCBI has a volunteer charter which includes sections on volunteer activities,

recruitment, support and standards. It gives a list of the rights and responsibilities of NCBI volunteers

#### *Evaluation and review procedures*

The NCBI has a policy of participation and consultation with the users of its services. It carries out surveys of its work. It has held 2 listening days, in Cork and Dublin in 1999. The NCBI has consumer advisory committees which work to ensure that services are relevant and customer-friendly.

## SERVICES

### INFORMATION SERVICES

The NCBI provides an extensive information service to members both in speech, in suitable written format and in braille. It has an information and resource centre at Whitworth Road, Dublin 9. This deals with enquiries from visually impaired people, their families, health professionals and members of the public. It has a website: [www.ncbi.ie](http://www.ncbi.ie)

#### *Publications*

The NCBI publishes a number of specialised books and magazines on tape and in braille (see library services below). It publishes an annual report. It publishes a bimonthly magazine called *NCBI News*.

#### *Library services*

The NCBI provides a range of library services for blind and visually impaired people. The library service operates from its Whitworth Road premises in Dublin and from the branch in Cork. One of its main library services is the 4-track talking book library. This is a stock of more than 70,000 titles including 2,000 taped books on high quality recording and read by professional actors. Catalogues are available in a range of formats to facilitate choice. These tapes all require a talking book machine, a special type of tape recorder. These machines are lent to anyone who joins the library free of charge. The books are sent by free post to individuals.

The NCBI library also has a braille library comprising 11,000 volumes in all. Braille is a system of raised dots on the page which a trained blind person can touch, read and write with the aid of a braille machine. The library has more than 2,000 books in braille (11,000 volumes). The braille collection includes children's books. The NCBI has adapted an educational series of books, *Springboard*, to braille and these are available through the library.

The library also produces audio copies of Irish published magazines including *Woman's Way*, *Ireland's Own*, *The Phoenix*, *RTE Guide* and *The Word*. There is a subscription fee for this service and users return their tapes for reuse. *Sceal Beo* is a free, twice monthly magazine produced by the NCBI, with a circulation of 800. *Newstape* is a fortnightly 90-minute tape of articles from national newspapers covering current events, sports, reviews and interviews. This service costs subscribers £5 per annum.

### *Research*

The NCBI has developed proposals to undertake research to examine the issue of registration north and south of the Irish border, in both rural and urban areas and has made applications to the EU and to the Health Research Board in this regard.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

#### *Low vision clinic*

The low vision clinic at Whitworth Road, Dublin 9 assists people who are having difficulty coping with their level of eyesight. The cost of aids prescribed at the clinic is usually met by the relevant health board.

#### *Mobility training service*

The NCBI provides mobility training so that people who have become significantly visually impaired can learn to move around again safely either by learning to use their residual vision or with a long-cane.

### **SUPPORT SERVICES**

The NCBI has an extensive national network of community resource workers who provide local support and other services to blind and visually impaired people in the locality. They have a broad work remit which includes assessment, emotional and counselling support, assistance in obtaining necessary rehabilitation and with environmental and housing issues, encouragement of participation in mainstream and specialised leisure pursuits, facilitation of access to education, vocational training and work and provision of support to local volunteers. The community-based staff provide a family support service for families with one or more children with a visual impairment. Part of the NCBI mobility training service includes practical support to restore an individual's confidence in the home and with tasks of daily living.

#### *Counselling services*

The NCBI organises counselling for individuals or their families who require assistance from skilled staff. The NCBI also has a network of qualified blind and visually impaired peer counsellors who work with the professional staff.

#### *Respite services*

The NCBI organises respite services.

#### *Equipment purchase or loan*

The NCBI has a shop at Whitworth Road, Dublin 9. It stocks a wide range of useful aids and appliances. These include tactile and speaking aids such as clocks, watches, key rings, mobility aids including canes, games and puzzles adapted for blind and visually impaired use, specialised writing and reading equipment and adapted items of daily living. The shop provides a mail-order service with a special electronic catalogue. The NCBI also sells computers and adaptive technology appliances. It provides an after-sales support service. The NCBI seeks to provide a competitive, retail service which also ensures aftercare, support and telephone assistance in the case of any difficulty.

## **RECREATION SERVICES**

The NCBI local staff organise holidays, outings and group activities with the assistance of volunteers.

## **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

The NCBI operates an employment support service funded under the EU Horizon Employment programme. It aims to develop an employment support structure to assist people with a visual impairment into training and/or employment. The NCBI plans to develop a personalised service which will identify and respond to the individual needs of each person availing of the service. The service includes:

- a personalised assessment of the person's skills, abilities and interests;
- an assessment of functional vision and provision of training/aid as appropriate
- information on further training and/or employment options;
- training in the uses of specially adapted technology such as speech, large print and braille displays to assist within the workplace;
- guidance and support in developing job seeking and interview skills; and
- assistance with finding a placement and with adaptation to the new work environment.

The NCBI staff involved in this service include the rehabilitation officer, information officer, employment development officer, technical officer and a locally-based community resource worker. This team works closely with the relevant vocational training agencies, local employment services, school and colleges.

### *Other training services*

Courses of 23 weeks' duration take place at Whitworth Road, Dublin 9 as a preliminary to people entering further work training. Some of the skills taught in these programmes are also taught on a one-to-one basis by members of the community-based staff.

### *Other employment-related services*

The NCBI gives information to employers on grant aid assistance from the National Rehabilitation Board (NRB) to facilitate the employment or modification of the working environment of a blind person. The NCBI may also provide equipment on loans for short periods until grant approval has been obtained.

## **HOUSING SERVICES**

The NCBI is a registered housing agency. It is currently investigating the need to become an active supplier of accommodation for visually impaired people.

## **INDEPENDENCE SERVICES**

The NCBI mobility training service is an independence service. The community resource workers' service specifically identifies personal independence as a primary goal.

## **ADVOCACY SERVICES**

The NCBI is the national non-governmental representative body for blind and visually impaired people in Ireland. It campaigns on their behalf, particularly in relation to education, access and employment issues. The NCBI has a number of policy statements in relation to children 0-5 years, preschool educational access, primary school entrance, integrated education and other provision for school-going children.

The NCBI has made pre-budget submissions. These have put forward specific, costed recommendations in relation to the blind person's pension, disability benefit and blindness, blind person's tax fee allowances, blind welfare allowance, car and mobility allowances, special communication provision and provision of aids and appliances. The NCBI lobbies for funding of its national service and media centre for blind and visually impaired people. It also seeks to influence policy and practice in the areas of transport access.

As part of the democratisation of the NCBI, participants at the listening days in 1999 made the suggestion that people who are registered with the NCBI should be given some statement of the scope of the services and their legitimate expectations of these services. NCBI staff will act as advocates for clients in seeking entitlements, in obtaining information and services.

### *Links with other organisations*

The NCBI has involvement with the National Association for Deaf People (NAD), the Irish Wheelchair Association (IWA), the Irish Council for People with Disabilities, St. Joseph's School for the Blind, the Central Remedial Clinic (CRC), Kerry Friends of the Blind and the Kildare Consumer Committee.

# NEUROFIBROMATOSIS ASSOCIATION OF IRELAND

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Contact: Maura Mannion

## NEUROFIBROMATOSIS

Neurofibromatosis (NF) is a genetic condition with dermalogical, neurological and orthopaedic effects. It affects about 1 in every 2,500 people. Fibromas (nodular growths) grow on nerve tissue and may be apparent on the surface of the body. These fibromas can also grow internally, resulting in complications which may require surgery. From an orthopaedic perspective, scoliosis, a bone malformation, may be present.

About 20% of people with NF have severe complications which impede their lifestyle, while 80% lead normal lifestyles, with some difficulties from time to time. At present, there is no treatment for NF as such, but any medical or surgical problems are dealt with as appropriate.

## INTRODUCING THE NEUROFIBROMATOSIS ASSOCIATION OF IRELAND

The Neurofibromatosis Association of Ireland was founded in 1985 by 3 people who wished to obtain information about their condition. Since that time, the organisation has grown to provide a range of information and support services. In the past decade, the gene responsible for neurofibromatosis has been discovered. This gives people with the condition considerable hope for the future. The Neurofibromatosis Association of Ireland wishes to see the establishment of a national, multidisciplinary clinic for assessment, treatment and research of the multifaceted condition. The association would like to see research undertaken into the condition.

The main issues confronting the association include the lack of core funding to employ professional staff, to run an office and to develop links at European level. The association is critical of the lengthy hospital waiting lists for diagnostic and surgical services and of the lack of public and political awareness of the importance of genetic services nationally.

## MEMBERSHIP AND BOARD STRUCTURE

The organisation has made contact with approximately 1,200 individuals with neurofibromatosis nationally. There is no branch structure. The association is a company limited by guarantee and its charity number is CHY: 6657. The board comprises 10 members who are elected annually and it meets monthly.

## INCOME AND EXPENDITURE

The Neurofibromatosis Association of Ireland operates a CE scheme, with FAS funding. It has received small once-off grants from State agencies for the purchase of equipment etc. The association fundraises by means of concerts, sponsored climbs, cycle rallies and golf classics.

## **STAFF**

The Neurofibromatosis Association of Ireland has 1 part-time staff member, who is a CE worker with relevant qualifications. The CE scheme is vital for the association. A part-time professional family support worker is also employed. In addition, the association has about 16 volunteers, mainly comprising board members and some others.

### *Training, monitoring and evaluation procedures*

The Neurofibromatosis Association of Ireland has enabled CE workers and volunteers to attend computer training at the Carmichael Centre. It has no in-house training, induction, recruitment or retention strategies. The association points to its adherence to European standards of accountability. It produces annual audited accounts. It considers that its regular newsletter and the Annual general meeting (AGM) are opportunities for the monitoring and review of its work. The association has no written safety or complaints procedures and no formal internal reporting mechanisms. It considers that, given the small number of people involved, regular personal contact is assured.

The Neurofibromatosis Association of Ireland has never undertaken an independent organisational or service user evaluation. It obtains service user feedback internally at its annual general meeting (AGM).

## **PREMISES**

The Neurofibromatosis Association of Ireland has an office desk at the Carmichael Centre. This centre has full disabled access. The association has its own telephone and computer and may avail of the extensive office facilities, i.e. fax, photocopying, postal franking etc. in the Carmichael Centre.

## **SERVICES**

### **INFORMATION SERVICES**

The Neurofibromatosis Association of Ireland provides booklets and lends videotapes to members. It also has an information leaflet about its activities. It attempts to obtain media coverage in the national newspapers and on radio. The family support worker provides information about the condition to relevant medical personnel including students and to teachers. The association publishes an annual report and a quarterly newsletter.

### **SUPPORT SERVICES**

The Neurofibromatosis Association of Ireland provides a personal and family support service through its part-time family support worker who responds to helpline queries and provides nonprofessional counselling and visiting.

**RECREATION SERVICES**

The Neurofibromatosis Association of Ireland travels with children with the condition to the UK summer camp each year. A qualified medical team is available at all times on the camp. The association also organises small informal meetings for members.

**ADVOCACY SERVICES**

The Neurofibromatosis Association of Ireland is the national representative body for people with neurofibromatosis and their families. It lobbies government departments. It has organised a letter campaign to TDs. It supports members' requests for services and entitlements.



## NORTH WEST THERAPY CENTRE, SLIGO

Address: Ballytivnan  
Sligo town  
Co. Sligo

Tel: (071) 44748  
Helpline: (071) 46067  
Fax: (071) 41943

E-mail: [mstherapy@eircom.net](mailto:mstherapy@eircom.net)

Centre manager: Sr. Mary Henry

### INTRODUCING THE NORTH WEST THERAPY CENTRE, SLIGO

The North West Therapy Centre, Sligo (the therapy centre) was established in 1993. Since its foundation, client numbers have increased from 6 to 180. The therapy centre provides support and treatment to people with multiple sclerosis and their families. It also seeks to provide a flexible service to other people with disabilities and to promote organisational links with other non-governmental disability service agencies. The aim of the service is to provide a treatment, management and support service for people with multiple sclerosis in the North Western Health Board region, as well as providing a limited service to people with the condition in north Roscommon and north Mayo extending to Crossmolina.

The main issues facing the therapy centre are its need of increased and ongoing funding and the lack of public and political awareness of the needs of people with disabilities. The therapy centre points to the lack of a neurology service in the north west area, the lack of accessible transport and of respite facilities as key concerns.

### MEMBERSHIP AND BOARD STRUCTURE

The North West Therapy Centre is a regional organisation. Services are provided to nonmembers. It is a company limited by guarantee. Its charity number is CHY: 10323. It has a board of 7 directors, 3 of whom must be people with disabilities. The board of directors meets 3/4 times yearly. The therapy centre has 3 trustees and a board of management, which includes 3 of the directors, a medical officer, the centre manager and a representative of the health board. One member of the board of management has a physical disability. This group meets monthly. The therapy centre also has a voluntary fundraising committee of about 10 people

### CALLS FOR MEDICAL SERVICES FOR THE NORTH WEST REGION

People with medical conditions, living in the north west, often face long waiting lists and long journeys to attend specialist diagnostic or treatment clinics. For people living in Sligo and Donegal, attending a medical (esp. neurological) or a surgical consultant may involve, at the minimum, travel to Galway and frequently means travelling up to 200 km to Dublin.

The entire journey may be a significant physical and emotional trial. Many people travel for periods of up to five hours to attend an appointment with the specialist and then face the journey home. People without their own private transport must travel by health board minibus. For people with medical card entitlements, the number of visits may be restricted and do not necessarily coincide with the time of greatest need.

Many people with neurological conditions, such as multiple sclerosis, who live in the north west region, consider that they do not have an adequate opportunity to discuss their particular concerns or to obtain sufficient specialist information about their conditions. They would like to see the appointment of a consultant neurologist for the north west region.

who meet every two weeks. None of these committees has upper or lower age limits on membership.

The therapy centre has service links with the North Western Health Board, the Community Therapy Services Hospital in Sligo, Sligo General Hospital, Abbeyview residence, Cregg Hospital, Center for Independent Living, Irish Wheelchair Association, MS Ireland community visitors scheme, the Peace and Reconciliation programme in Monaghan and Drumcoo Centre.

#### **INCOME AND EXPENDITURE**

The North West Therapy Centre receives about £120,000 per annum in direct financing and has a number of "in kind" arrangements with both statutory and voluntary agencies in the area. The North Western Health Board (NWHB) gives a core grant of £40,000 and also pays the salaries of the manager and the counsellor at the therapy centre. The therapy centre has received a grant from the Peace and Reconciliation programme in relation to its cross-border service links. The centre also receives approximately £60,000-£70,000 per annum through its fundraising activities and from charitable donations and bequests. It has made application to the national lottery fund for £20,000 to equip its newly-built extension. The therapy centre spends about £120,000 per annum, mainly on a range of part-time staff.

#### **STAFF**

The North West Therapy Centre has 13 staff members. The manager and a counsellor are employed by the NWHB and assigned to the centre. The centre directly employs a full-time assistant manager, an administrative secretary, 2 part-time physiotherapists, 2 part-time reflexologists, 2 part-time care assistants, 2 part-time masseuses, and funds the monthly attendance of a dietician. In addition, the therapy centre will employ extra physiotherapy or speech and language therapy assistance when required, and also sources and funds specialist family psychotherapy services. All staff have necessary or relevant qualifications.

#### *CE scheme*

The therapy centre has 2 CE workers who are employed on a CE scheme operated through the social services department of the NWHB. The CE scheme is of limited but real value to the therapy centre. The success rate of the 3 previous CE workers in obtaining employment is 100%.

#### *Volunteers*

The therapy centre has 3 voluntary drivers. The EU Peace and Reconciliation funds provide finance for some of the costs associated with the transport service of the therapy centre.

#### *Training, monitoring and evaluation procedures*

The North West Therapy Centre does not operate any accredited training programmes for staff, CE workers or volunteers. It has in-house training and induction programmes for staff, CE workers and volunteers. It has recently commenced an in-house support meeting for staff, CE workers and personnel from other voluntary agencies. The therapy centre has stated written safety, complaints and internal reporting mechanisms. The therapy centre has a safety statement for volunteers.

The North West Therapy Centre undertook an independent service user evaluation in 1995. This comprised a questionnaire sent to service users requesting their views. The results indicated considerable satisfaction. The therapy centre has not had an independent or internal organisational evaluation.

#### **PREMISES**

The therapy centre has a main office building, a waiting room, treatment rooms and a kitchen area. It is fully accessible. The centre has computers, drop-in facilities and meeting rooms. The therapy centre commenced an extensive building programme in September 1999 which, when completed, will almost double the available treatment space and create new opportunities for assessment. This building project is being undertaken *gratis* by the Construction Industry Federation (CIF).

## **SERVICES**

#### **INFORMATION SERVICES**

The North West Therapy Centre provides information to people with multiple sclerosis and their families. The centre's waiting room stocks a large range of information leaflets. Staff members follow up information enquiries. The therapy centre operates a helpline: 071-46067. People with a wide range of disabilities and members of their families telephone the centre, seeking general information and advice about social welfare entitlements, housing and transport grant-aid and therapeutic opportunities. Staff refer individuals to the local assessment services for vocational and employment opportunities. Staff from the therapy centre run seminars biannually. These are held in local hotels and are usually on a topic related to multiple sclerosis.

#### *Publications*

The therapy centre publishes an annual report. This is used for general information, publicity and fundraising purposes.

#### *Research*

Using EU Peace and Reconciliation funding, the therapy centre has undertaken research in 1999 on the attitudes of young adults to their parents with multiple sclerosis. The therapy centre has also cooperated with research undertaken by the Sligo Institute of Technology. The centre donates a small sum each year to the ongoing myelin research project at the University of Dublin, Trinity College.

#### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

##### *Palliative services*

The therapy centre provides a palliative service. It has access to 2 bed placements in St. John's Hospital, Sligo. One of these places is routinely used for palliative care.

### *Therapy/rehabilitation services*

Physiotherapy, occupational therapy, speech and language therapy, counselling and the services of a dietician are available in the therapy centre. In addition, the centre offers reflexology and massage. It has a hyperbaric oxygen apparatus, which increases the oxygen level in the body. This is a therapy which was popular in the past and remains of value to some people with multiple sclerosis.

### **SUPPORT SERVICES**

The centre's core role is to provide personal and family support services to people with multiple sclerosis. It runs informal support networks. It operates a helpline.

### *Support training service for carers*

The therapy centre provides training in lifting and handling for family members who provide assistance to a disabled person.

### *Counselling services*

The therapy centre has a counsellor who works full-time. Every new client at the centre is offered the opportunity to speak with the counsellor. At any subsequent time, the client may also request counselling. On average, the counsellor assists 40 individuals/families in a month. The centre is currently examining ways to provide a shared counselling service with other non-governmental agencies working in the region.

The centre also provides specialist family psychotherapy for a small number of families. This service is paid for by the centre on a fee per session basis. The centre has links with and cooperates with the St. Michael's Family Life Centre, a specialist counselling service.

### *Respite services*

The therapy centre provides hospital-based respite services in St. John's Hospital, Sligo. The centre has access to a ½ bed place in a specially designed unit which has bedroom/sittingroom and *ensuite* facilities. Individual clients have used this facility as a respite break and as a means of obtaining intensive therapy. The centre also has links with Abbeyview, the local Cheshire home and, occasionally, people will stay at the home and attend the therapy centre. The centre has paid for short-term, nursing home accommodation in order to provide respite for an individual or family.

### *Financial support*

The therapy centre provides financial support. The welfare subcommittee of the board receives anonymous applications, through the centre manager, and makes allocations under various headings. Items that have been financed include specialised equipment, e.g. water chairs, attendance at specialist neurological clinics, assistance with the purchase of private transport and funds to obtain respite/holiday breaks. For expensive items of equipment, e.g. rest/riser recliner chairs, the therapy centre will often provide half of the cost and the NWHB will contribute the remainder.

## **ADVOCACY SERVICES**

The therapy centre seeks to assist people with physical disabilities in whatever way is possible. Staff of the centre are in direct contact with health board administrative personnel and lobby for improved services regionally, and for individual clients. The manager of the therapy centre is a member of the health board consultative group dealing with physical and sensory disability, of the coordination committee and of a health board committee examining the issue of long-term care. The centre seeks to assist people with disabilities to be self-advocates and encourages them to claim entitlements and necessary services, equipment and appliances.

### *Links with other organisations*

The therapy centre has active links with many of the North Western Health Board services in Sligo, including St. John's Hospital and the community occupational therapy service. It also has links with other non-governmental service organisations including the Cheshire home, Irish Motor Neurone Disease Association and Brainwave - the Irish Epilepsy Association and has provided services for members of these organisations. The centre has contact with the MS Society of Ireland. It also has cross-border links with a similar group in Drumcoo, Enniskillen.

## **ORDER OF MALTA ENTERPRISES**

**Address:** Industrial Estate  
Donore Road  
Drogheda  
Co. Louth

**Tel:** (041) 9836145

**Fax:** (041) 9833910

**E-mail:** oom@tinet.ie

**Contact:** Sr. Rosaleen

### **INTRODUCING ORDER OF MALTA ENTERPRISES**

Order of Malta Enterprises was founded in 1969 to train young adults with special needs to attain their full potential. The organisation's mission is to work in consultation with people with disabilities to provide them with employment opportunities and personal development and betterment. It points to shortage of finance and vacancies in its training unit as principal concerns.

### **MEMBERSHIP AND BOARD STRUCTURE**

Order of Malta Enterprises is not a membership-based organisation. The board of management comprises 10 members who meet monthly.

### **STAFF**

Order of Malta Enterprises employs 16 paid staff members, of whom 3 are administrative and all are qualified. The organisation does not participate in CE schemes and has no volunteers. Order of Malta Enterprises operates induction, accredited and other in-house training programmes for staff. It has written safety, complaints procedures and internal reporting mechanisms. It has undertaken independent and internal organisational and service user evaluations within the last 5 years.

### **PREMISES**

Order of Malta Enterprises has excellent facilities, fully accessible with computerisation. The premises have no meeting or drop in facilities at present but there are plans to develop these in the near future.

## **SERVICES**

### **INFORMATION SERVICES**

Order of Malta Enterprises operates an information service to trainees and family members. It has a website. It runs media/publicity campaigns in the region. It publishes an annual report and a newsletter.

### **MEDICAL /NURSING/THERAPEUTIC SERVICES**

The workshop has continuous nursing supervision, with an opportunity for consultations for trainees to discuss any problems.

### **SUPPORT SERVICES**

Order of Malta Enterprises provides personal and family support services. It offers personal, groups and family counselling. It has plans to develop accommodation for respite purposes.

### **RECREATION SERVICES**

Order of Malta Enterprises provides ongoing recreation activities, sports and holidays.

### **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

Order of Malta Enterprises provides vocational assessment, training, placement and other vocational services. It currently provides services to 80 trainees.

### **HOUSING SERVICES**

Order of Malta Enterprises provides emergency accommodation and housing.

### **ADVOCACY SERVICES**

Order of Malta Enterprises encourages self advocacy in all trainees.

## **POLIO FELLOWSHIP OF IRELAND**

**Address:** Training and day activity services  
Park House  
Stillorgan Grove  
Stillorgan  
Co. Dublin

**Tel:** (01) 2888366/2886468/2833481/2/3

**Fax:** (01) 2836128 (training centre)

**Tel/fax:** (01) 2889163 (day centre)

**E-mail:** parkhouse@rehab.ie

**Contact:** Christine Flynn (training centre)  
Sheelagh Collier (day activity centre)

### **INTRODUCING THE POLIO FELLOWSHIP OF IRELAND**

The Polio Fellowship of Ireland was founded in 1949 to represent and support post-polio adults and children. Over the decades, it has developed a wide range of services for people with polio. In the 1960s, it acquired the Park House property and opened its vocational residential rehabilitation centre. During the 1970s, it developed services in training and rehabilitation for people with physical disabilities. In 1980, it set up a day activity centre. In 1986, it amalgamated with the Rehabilitation Institute (now the Rehab Group). In the past decade, it has sought to consolidate its existing services and to expand its remit in education and training to meet the needs of its clients.

### **MEMBERSHIP AND BOARD STRUCTURE**

Polio Fellowship of Ireland is not a membership-based organisation. It has no branch structure. It is a company limited by guarantee. Its charity number is CHY: 5380. The board comprises 13 members. It meets 6 times a year. There are no upper or lower age limits on board membership.

### **INCOME AND EXPENDITURE**

Polio Fellowship of Ireland obtained almost £400,000 from the conquer and care lotteries and from the charitable lotteries fund, and an additional £82,467 from the Polio Fellowship of Ireland Help Society in 1998. It also received European Social Fund (ESF) financing of £394,018 for its vocational training programmes. It obtained £286,286 from public authority sources: £177,438 in grant aid for rehabilitation and £108,848 from the Eastern Health Board for the day activity centre. Total overhead expenses came to £763,405 in 1998.

Administration expenses came to £566,423 of which £381,377 went to salaries and related costs and £31,888 on external trainers. The total for trainees' expenses for 1998 came to £164,449.



## **STAFF**

The day activity centre has 9 staff members, including an administrator, art teacher, physiotherapist, speech and language therapist, care attendants and drivers. The training centre has 12 staff members, including an administrator, instructors, a teacher and support staff.

### *CE scheme*

The Polio Fellowship of Ireland's day activity centre participates in a FAS CE scheme which provides care workers for the centre. Polio Fellowship of Ireland finds it impossible to fill CE vacancies due to poor rates of pay. Rates of subsequent mainstream employment for CE workers are good.

### *Volunteers*

Polio Fellowship of Ireland's day activity centre has 10 volunteers who help with outings, transport, shopping and social support. Polio Fellowship maintains links with organisations operating preparation for retirement courses, as one means of volunteer recruitment.

### *Training, monitoring and evaluation procedures*

Polio Fellowship of Ireland has a full induction programme, with courses in disability management, trainer skills, manual handling, first aid and other appropriate training. Polio Fellowship of Ireland has written safety, complaints, reporting and monitoring procedures. It has undertaken an external organisational review in conjunction with the Rehab Group. It had an SI95 National Accreditation Committee audit of its training services in 1998. It has ongoing internal reviews throughout the year.

## **PREMISES**

Park House was built in 1880. It is set in its own grounds (c. 3 acres) in Stillorgan, south county Dublin. It has an art studio, a garden centre open to the public, catering training area with full dining room, and an education and learning centre. Residential accommodation for 20 students is also on the site.

## **SERVICES**

### **INFORMATION SERVICES**

Polio Fellowship of Ireland provides brochures on its various vocational training and day activity services. It publishes an annual report.

### *Media campaigns*

Polio Fellowship of Ireland has ongoing contact with the media to promote both the day activity and training services.

### *Research*

Staff are involved in a number of research projects, both internally and externally.

## **MEDICAL/NURSING/THERAPEUTIC SERVICES**

### *Therapeutic services*

The Polio Fellowship of Ireland's day activity centre provides physiotherapy, speech and language therapy, occupational therapy and chiropody. Transport to and from the centre is available to people living between little Bray and Mount Merrion in Co. Dublin.

## **SUPPORT SERVICES**

Polio Fellowship of Ireland has a day activity centre at Park House. This was established in 1980 and provides services to people with disabilities, between the ages of 18 and 70, who are unable to avail of work full-time. The centre provides a range of activities which seek to develop or maintain independence. It also offers a social activities programme to promote communication and self-confidence. Among the many options open to participants are arts and craft, group discussions and outings. The centre provides light meals.

### *Counselling services*

Counselling support is provided in the day activity and training centres, when requested.

## **VOCATIONAL /TRAINING/EMPLOYMENT SERVICES**

Polio Fellowship of Ireland has extensive experience in the operation of a range of training programmes for people with special needs. It has attained *approved centre* status for the quality of its vocational training services from the National Accreditation Committee (NAC). As part of these courses, students may avail of additional classes in literacy and numeracy if required. Training is also available in assertiveness, confidence building, independent living skills and job seeking skills through a learning support teacher who provides individual support to each student. Students on the courses obtain a weekly training allowance, uniforms/safety wear and course materials free of charge. Students may also avail of the lunch facilities and will be provided accommodation on request.

### *Open days for prospective students*

Park House's training centre holds open days on the last Thursday of each month (excepting December). Phone booking is necessary.

### *City and Guilds certified training*

Polio Fellowship of Ireland runs a personal care assistant course (C&G 3250), which gives a City and Guilds qualification. This 2-year course has practical and theoretical modules.

### *CERT recognised training*

Polio Fellowship of Ireland runs a number of CERT (the State Tourism Training Agency) vocational training courses. These courses are for people over the age of 18 years who need specialised training and who are registered with the National Rehabilitation Board (NRB).

These courses are:

Catering and hospitality is a 2-year training course in food preparation, cooking, food and beverage service. The centre has a modern industrial kitchen where students acquire the skills and knowledge necessary to take up employment in the catering industry.

Accommodation services is a 2-year course with practical and theoretical modules which gives students the necessary experience for the hotel and tourism industries. The students on this course learn basic skills at the centre and link with the local hotels to reinforce and transfer skills and knowledge.

#### *TEAGASC certified training*

Horticulture is a 2-year course, certified by TEAGASC (Agriculture and Food Development Authority), with practical and theoretical modules to equip students with the skills required for this industry. The gardens at Park House provide an ideal training location from which students move on to work experience and work placement.

#### *NCVA accredited training*

Polio Fellowship of Ireland offers a modular course with NCVA (National Council for Vocational Awards) which seeks to assist students to obtain employment in the art, design and the communications industry. The course is based in a fully equipped art studio at Park House. Modules include drawing, painting, sculpture, combined materials, communications and work experience.

#### *Employment services*

The Park House unit provides employment for disabled people in its offices and day activity service and in a sheltered packaging division. Throughout each course, students are supported through the use of individual programme plans to avail of work experience placements, locally, nationally and internationally. At the end of the training course, students complete job preparation/job retention modules and are assisted to find suitable employment.

### **HOUSING SERVICES**

#### *Accommodation service*

Up to 20 students attending courses at Park House may avail of residential accommodation at the site. This accommodation is offered on a 5nights per week basis and is located on the first and second floors.

### **INDEPENDENCE SERVICES**

Polio Fellowship of Ireland considers that its training courses and day activities centre seek to improve the lives of people with disabilities by enabling maximum independence for each individual. Clients and students are supported and encouraged to be as independent as they wish to be. The centre encourages this through all its services, i.e. the individual programme plans for students and with representative groups of clients and students.

### **ADVOCACY SERVICES**

Polio Fellowship of Ireland has ongoing contacts with the Department of Health and Children, the Department of Social, Community and Family Affairs and the training certification bodies.

# POST POLIO SUPPORT GROUP

Address: Carmichael Centre  
north Brunswick Street  
Dublin 7

Tel: (01) 873 0338

Fax: (01) 4549237

E-mail: [ppsg@eircom.net](mailto:ppsg@eircom.net)

Website:

[www.homepage.eircom.net/~ppsg](http://www.homepage.eircom.net/~ppsg)

Chairperson: Jim Costello  
Hon secretary: Joan Bradley  
Treasurer: Mary McEvoy

## INTRODUCING THE POST POLIO SUPPORT GROUP

In 1993, 3 polio survivors formed the Post Polio Support Group (PPSG). The object from the outset was to assist people who were experiencing the Late Effects of Polio including post-polio syndrome (PPS). As a result of media publicity surrounding the establishment of the group, many people experiencing the late effects of polio contacted the organisation. A significant problem for these people was the lack of information available to them about their condition. The PPSG began to disseminate information and held a one-day national conference in May 1994. The group had an

input in designating the neuromuscular clinic in Beaumont Hospital as the specialist medical location for people with polio. In March 1999, the group organised a 2-day international conference on PPS with speakers from the USA, Denmark and Ireland. Since then, the PPSG has provided information and support to polio survivors, has sought to improve their general situation in Ireland and to raise awareness among the medical profession about the problems some of these people now face.

## MEMBERSHIP AND BOARD STRUCTURE

The PPSG has a membership of about 300 people nationally. The group does not have a formal branch structure, but has voluntary representatives in each health board region. It is a company

### LATE EFFECTS OF POLIO

During the 1940,'s and 1950's, the debilitating disease, poliomyelitis (polio), struck down many people in Ireland. Some were not paralysed, others were partially paralysed and recovered, while others were paralysed partially or severely for life.

In Ireland, at present, there are approximately 7,000 polio survivors. About 20 to 40 years after their original infection with polio, many survivors are now experiencing new symptoms, which often require medical advice and treatment. This condition is known as the Late Effects of Polio or post polio syndrome (PPS). A much rarer form is called post polio muscular atrophy.

These symptoms are not age-related and usually appear in the form of:  
pain in muscles and joints;  
lack of strength and endurance, with increased muscle weakness and fatigue;  
respiratory and swallowing difficulties, often with problems relating to sleep;  
severe intolerance of the cold; and  
decline in the ability to carry out customary daily activities such as walking.

This condition is recognised internationally and research is ongoing. While there is no known cure, much can be done to alleviate the symptoms and enable the retention of an independent life, often requiring some modification of lifestyle.

limited by guarantee. Its charity number is CHY: 11356. The board of the PPSG consists of a maximum of 11 members. It is gender-balanced and all current members are polio survivors. Membership rotates annually and the board has 8-10 meetings per annum.

#### **INCOME AND EXPENDITURE**

In 1998, the organisation had a total income of £20,313. This included a once-off grant of £10,500 to fund a conference, held in March 1999. The main source of funds is *via* an annual grant from the Polio Fellowship of Ireland to cover general running expenses. The PPSG receives no European or FAS CE funding, but has received funding from a number of health boards for specifically designated purposes. The PPSG does not seek charitable funding, but has received some unsolicited donations in the past. The PPSG spends about £10,000 per annum on all of its services.

#### **STAFF**

The PPSG employs no staff. All of its activities are carried out on a voluntary basis. The PPSG has no induction or training programmes for its volunteers. This poses no problem at present, given the size of the organisation and the personal involvement of all existing volunteers. The PPSG would be interested to develop training programmes for volunteers, including accredited programmes. As a small, entirely volunteer organisation, it has not undertaken an independent or internal service user or organisational evaluation.

#### **PREMISES**

The PPSG shares an office desk in the Carmichael Centre.

## **SERVICES**

#### **INFORMATION SERVICES**

##### *General information*

The PPSG has a monitored answer phone to respond to queries and to requests for support from polio survivors. The PPSG has a website [www.homepage.eircom.net/~ppsg](http://www.homepage.eircom.net/~ppsg) which provides group contact details and also gives links to other relevant websites.

##### *Specialised information*

The PPSG publishes a newsletter for members and holds area information meetings, coordinated through the voluntary area representatives. At its annual general meeting (AGM), the PPSG includes a medical lecture on an issue of interest or concern to members.

##### *Public awareness*

The PPSG promotes its perspective by the dissemination of literature and posters. It has run a media campaign with the voluntary assistance of a professional consultant. The PPSG intends to produce an annual report.

**SUPPORT SERVICES**

The PPSG provides individual and family support by telephone and by personal visits from the voluntary area representatives. These area volunteers also assist in providing and maintaining support networks. The PPSG wishes to establish a professional counselling service for members.

**ADVOCACY SERVICES**

The PPSG is the national representative body for polio survivors with the Late Effects of Polio. The main issue facing PPSG members is the often substantial financial cost incurred in managing the Late Effects of Polio. Historically, polio survivors have not been included on the long-term illness list. As a result, they now face economic hardship because of the unanticipated occurrence of the Late Effects of Polio. The PPSG campaigns for eligibility of polio survivors for long-term illness benefits, for flexibility and understanding in relation to medical card applications from polio survivors, for improved funding and more ready availability of aids and appliances, of physiotherapy, occupational therapy and professional counselling services nationally.

The PPSG has ongoing contact with politicians, health board officials and government departmental staff. It has made a presentation on behalf of polio survivors to the Joint Oireachtas Committee on Health and Children.

# REACH IRELAND

## THE ASSOCIATION FOR CHILDREN WITH LIMB DEFICIENCY

Address: Fair Stream  
Hedge Road  
Garristown  
Co. Dublin

Tel: (01) 8354953  
Fax: (01) 8427788

Website: [www.reach.org.uk](http://www.reach.org.uk)

Contact: Christopher/Rita Creamer

### INTRODUCING REACH IRELAND

Reach Ireland was formed in 1990 as a regional branch of Reach in the United Kingdom (UK). Reach has a number of branches throughout the United Kingdom and has links with other independent associations in France, Hungary and Italy. The Irish branch was set up as a parent's support group, providing information about limb deficiency and its treatment. In the past 10 years, the Irish organisation considers that it has made significant progress in highlighting the lack of medical and specialised surgical and orthopaedic services for children born with limb deficiency in this country. It has also developed excellent contacts with the medical profession here and abroad and keeps abreast of all developments in the area.

Reach Ireland is a small, entirely voluntary group. It seeks funding for the ongoing research into the causes of limb deficiency as a first step in treatment and prevention. It considers that the Irish State should collect and collate figures on all birth-registered disabilities, including limb deficiency. It points to the enormous regional variation in services for children with limb deficiency and it argues for services as a right. It has campaigned consistently for the inclusion of limb deficiency on the long-term illness list. It wishes to see the provision of a medical card to every person with a limb deficiency.

### LIMB DEFICIENCY

Limb deficiency is relatively rare and may be present at birth or may be caused through accident. Limb deficiency at birth is due to problems of early foetal growth, although the exact cause(s) for this failure of growth are unknown. The limb deficiency may be a total or partial absence of a limb or may involve limited bone growth or problems with the fingers or toes.

Some people with limb deficiencies require surgery, sometimes over a period of years. For other individuals, prosthetics such as an artificial arm or leg are an appropriate response. In some cases, use of aids or adapted implements is of benefit.

One of the key issues at present is to find the cause(s) of limb deficiency present at birth. With the now routine use of ultrasound to examine foetal growth, expectant parents may learn that their unborn child has a limb deficiency. Whether parents find out before or after birth, they usually require support and a lot of information to help them understand what has happened and how they can move forward.

Children with limb deficiency may need assistance at school and a small number may require a personal assistant to allow them to attend mainstream schooling.

## **MEMBERSHIP AND BOARD STRUCTURE**

Reach Ireland is in contact with about 235 families throughout the country. It has a committee of members, who meet as the need arises. One of the committee members has a limb deficiency and there are moves to include young people with limb deficiency more fully in the organisation to harness their knowledge for the group. The chairman of Reach Ireland is one of the trustees of Reach in the UK. Reach Ireland, as a regional branch of Reach, has formal voting rights at the AGM, held in different locations in the UK.

## **INCOME AND EXPENDITURE**

Reach Ireland has no regular income. For the past number of years it has organised a quiz night hosted by the TV personality, Jeremy Beadle. This raises funds which are channelled through the central UK-based organisation into a bursary fund for nonmedical assistance, some of which is redistributed to Irish members. Reach obtains no funding from any statutory source in this country. In the past, it has obtained once-off funding from People in Need.

## **STAFF**

Reach Ireland has no paid staff. It calls on variable numbers of volunteers at national and local level when needed.

### *Evaluation procedures*

Reach in the UK has been evaluated and assisted by CAFCERTS, a British body which assists the voluntary sector. Following on this initiative, the activities of Reach groups throughout Europe are under review. Initiatives, particularly in relation to young adults with limb deficiency have started. Reach Ireland surveyed its membership a number of years ago in order to shape its services.

## **PREMISES**

Reach Ireland operates from the family home of one of the members.

# **SERVICES**

## **INFORMATION SERVICES**

Reach Ireland provides a number of information services to members and to people making general enquiries. It provides one-to-one information to parents of children newly diagnosed with a limb deficiency. It distributes all of the information coming from Reach UK. It advertises the Reach UK website. It has undertaken focussed media campaigns in Ireland. It has approached each of the maternity hospitals to advertise its presence and to encourage contact with new parents.

### *Publications*

Reach in the UK publishes an annual report and a quarterly newsletter *Within Reach*. Reach UK also publishes a number of informative booklets outlining what is known about limb deficiency and giving details of surgical and non-invasive rehabilitation. Reach Ireland has a



simple explanatory booklet *My story* which outlines the causes and effects of upper limb deficiency and is recommended for use in the primary classroom to explain the condition.

#### *Research*

Some funds are used to assist with research into the causes and treatment of the condition, when appropriate.

#### **SUPPORT SERVICES**

Reach Ireland provides peer support to parents with a child with a limb deficiency. Throughout the country, parents in this position will visit and support others. For older children and young adults with limb deficiency, Reach Ireland has used the Irish Wheelchair Association's peer counselling service.

#### *Financial support*

Reach Ireland, through Reach in the UK, provides financial support for people with a limb deficiency. This includes purchase of educational aids, computers and one-handed keyboards, sporting and musical equipment. Finance has also been provided to obtain professional counselling.

#### *Equipment loans*

Reach UK loans modified sports and musical equipment to people with limb deficiency.

#### **RECREATION SERVICES**

Reach Ireland hosts a Christmas party and a summer picnic. The Reach UK Annual general meeting (AGM) has developed as a family weekend. A regular feature is the participation of the British Paralympics team. They encourage all the children with limb deficiency attending the conference to join in various on-the-spot sporting activities.

#### *Sporting activities*

The range of sporting activities enjoyed by people with limb deficiency is vast and includes running, swimming, waterskiing, football, cycling, riding and golf. These activities are made available to Reach Ireland members on holidays arranged through Reach in the UK.

#### **ADVOCACY SERVICES**

Reach Ireland acts as a national advocate for parents of and people with limb deficiency. The group has had significant contact in the past with the Department of Health and Children, but without any results in terms of improved services or approach.

The group assists and advises parents seeking to modify their homes to facilitate a child with limb deficiency and has liaised with local authorities in this regard. Reach Ireland encourages all members to lobby for appropriate services. Some individual members have taken direct action with considerable success.

## **REHAB GROUP**

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Dublin 4

**Tel:** (01) 2057200

**Fax:** (01) 2057211  
(01) 2057211

**E-mail:** [info@rehab.ie](mailto:info@rehab.ie)  
**Website:** [www.rehab.ie](http://www.rehab.ie)

### Rehab Group staff:

Chief executive: Frank Flannery  
Deputy chief executive/director of finance: Tim Walsh  
National Training and Development Institute (NTDI): Dorothy Gunne  
Rehab Foundation chief executive officer: Stephen Farrelly  
Director of commercial development/Gandon Enterprises chief executive officer: Gina Quin  
Director of public affairs and care services/chief executive officer RehabCare: Angela Kerins  
National representative council chief executive officer: Paddy Doyle  
Director of Rehab Lotteries: Dr. John McGuire  
Director of programme development: Dr. Donal McAnaney  
Project director and group financial controller: Keith Poole  
Personnel manager: Ken O'Brien  
Group internal audit manager: Eamonn O'Beirne  
Public relations manager: Chris Macey

### **INTRODUCING THE REHAB GROUP**

The Rehab Group is an independent, not-for-profit organisation delivering training, employment, social care and commercial services to promote equality. Founded as the Rehabilitation Institute in 1949 to help survivors of tuberculosis to reintegrate into society, the organisation's client base now includes people with disabilities and other disadvantaged groups and individuals. The Rehab Group is involved in activities in more than 100 locations in Ireland and the United Kingdom, providing services for 18,500 people each year. It employs 1,800 people, 20% of whom are people with disabilities.

In Ireland, the Rehab Group's activities are coordinated by the following main divisions: the National Training and Development Institute (NTDI), Gandon Enterprises Ltd., RehabCare, the Rehab Foundation, the National Representative Council, the Department of Programmes and Research and Rehab Lotteries. The group is committed to providing services that are progressive, innovative and entrepreneurial. It aims to lead in promoting social integration, economic independence and equal opportunities for all, especially people with disabilities. The Rehab Group is committed to working in partnership with people with disabilities, State

bodies and non-governmental organisations to implement the recommendations of the Commission on the Status of People with Disabilities. It is also involved in development projects in Kenya and South Africa and has non-governmental organisation (NGO) status with the United Nations (UN).

#### **MEMBERSHIP AND BOARD STRUCTURE**

In 1997, the Rehab Group established a national representative council (NRC) to represent the group's service users. This now has more than 2,100 members in local advisory committees.

The Rehab Group is a company limited by guarantee. Its charity number is CHY: 4940. The Rehab Group activities are overseen by a non-executive board of directors. NTDI, Gandon Enterprises Ltd., RehabCare and the Rehab Foundation also have their own boards of directors.

#### **INCOME AND EXPENDITURE**

The Rehab Group currently has an annual turnover of more than £74m. This comes from a variety of sources including European Union (EU) and Irish State grants, income from commercial services and fundraising revenue. It is the group's aim that its core services should be self-financing. The Rehab Group has a number of divisions. Each of these is described below.

#### **THE NATIONAL TRAINING AND DEVELOPMENT INSTITUTE (NTDI)**

The National Training and Development Institute (NTDI) is Ireland's largest non-governmental training organisation with more than 40 purpose-built centres nationwide, catering for more than 2,500 students each year. Its objective is to equip people, at a disadvantage in the labour market, with the skills they require to build lasting careers in jobs that reflect their interests and abilities. This is achieved through flexible training, education and employment access and enterprise development services which have enabled more than 20,000 people to join the workforce in careers as diverse as agriculture and architecture.

The majority of NTDI's student body comprises people with disabilities, although, increasingly, other groups and individuals facing obstacles in the search for work are using its services. The organisation offers more than 40 different vocational programmes which carry nationally and internationally recognised certification and are designed to lead either directly to jobs or to progression to further education. NTDI has a multi-disciplinary team of some 500 teachers, trainers,

#### **NTDI TRAINING CENTRES**

NTDI operates training centres in Athlone, Arklow, Bantry, Bray, Carlow, Castlereagh, Castlebar, Cavan, Clonmel, Cork (Douglas, Hollyhill) Dublin (Ballyfermot, Park House in Stillorgan, Roslyn Park in Sandymount, Swords, Tallaght) Dundalk, Galway, Kildare, Kilkenny, Lifford, Limerick, Longford (Coolamber), Monaghan, Mullingar, Navan, Portlaoise, Sligo, Tralee, Tullamore, Waterford and Wexford.

curriculum development officers, psychologists and employment support staff. Additional services are provided, such as compensatory education, job search skills, work-related social skills, personal development and counselling as, and when, required.

The NTDI programmes are provided through its national network of centres, employment locations and through distance learning opportunities. All NTDI centres are accredited by the National Accreditation Committee (NAC). NTDI is also involved in a number of projects designed to open up new career opportunities for people with disabilities as well as increasing the employability of specific groups who are at a disadvantage in entering the jobs' market. These projects include:

- Art access which leads to careers in various artistic pursuits;
- Media access which provides training for jobs in print and broadcast journalism;
- Selfstart which assists participants to set up their own businesses;
- Sound access which leads to a variety of jobs in the music industry;
- Le ceile which aims to increase the job prospects of people with disabilities through a system of retraining in a business and manufacture setting; and
- Connect which aims to increase the future employability of ex-offenders.

In addition, NTDI has provided an electronics course for people who are long-term unemployed, in conjunction with the Ballymun Partnership in Dublin. It also runs a number of evening courses. These include the *Agrinet* programme which provides computer skills to farmers in the midlands and northeast, along with health and safety modules for industry in various locations around the country.

#### **GANDON ENTERPRISES LTD.**

Gandon Enterprises Ltd. provides integrated employment for people with disabilities in 9 businesses located across Ireland. In total, 504 people are employed under the Gandon Enterprises Ltd. umbrella, including about 231 workers with disabilities. Gandon Enterprises Ltd. wishes to have people with disabilities comprise at least 50% of its workforce as part of an overall policy that seeks to create a 50:50 balance of people with disabilities and able-bodied employees throughout the group.

**Gandon Enterprises Ltd. companies**  
Harrison's Food Company  
Precision Workwear  
Rehab Recycling Partnership  
Response Electronic Manufacturing  
Galway Corrugated Cases  
Hats of Ireland  
Connect Industries  
The Mill Enterprise  
Kilkenny Box

Each of the Gandon Enterprises' companies provides a supported environment within the workplace for people with disabilities, through the provision of adapted working environments and working procedures, facilitative supervision and management and the provision of *Workpath* services through its sister company, RehabCare. *Workpath* services provide a comprehensive support service for the individual, incorporating matters external to the work environment which may impact on each person's ability to maintain paid employment.

The company operates with a subsidy from the Irish government, (under a pilot programme for the employment of people with disabilities), towards the additional costs of employing significant numbers of people with disabilities within its workforce. Gandon Enterprises Ltd. provides a nett economic benefit to Irish society and to the government by providing employment for people who were previously unemployed and/or receiving social welfare benefits.

## **REHABCARE**

RehabCare provides a range of community-based, direct health and social care services for some 1,500 people with significant physical, sensory and learning disabilities, people with mental health difficulties, older people, people who are long-term unemployed and carers. These services operate in more than 20 locations across Ireland and include:

### **SUPPORT SERVICES**

#### *Resource centres*

RehabCare resource centres aim to assist people with disabilities to achieve their full potential and a better quality of life. They provide a comprehensive range of developmental programmes which promote independent living and enable their clients to participate actively in their local communities. RehabCare has also established cooperatives at the resource centres where work is carried out for local businesses and all the earnings are distributed among the clients. Some clients opt to take part in supported employment programmes and work part-time in local museums, hotels, hairdressing salons and shops where they are paid the usual rate of pay for that employment by the employer. The resource centres also provide day and evening social and leisure programmes. Clients are encouraged to use mainstream sports and recreation facilities and activities whenever possible.

#### *Carelink (home-based services)*

RehabCare operates home help, home support and home-based respite services for people with disabilities, older people and their carers under the brand-name of *Carelink*. The programme assists hundreds of people to continue living in the family home rather than moving into residential facilities. It also provides a support and advisory service for carers, who would otherwise be isolated and housebound, caring for a relative.

#### *Respite services*

In addition to the *Carelink* respite service, RehabCare provides centre-based services in designated accommodation for people with significant physical, sensory and learning disabilities. These give a break for carers and provide possibly the only opportunity for many people with disabilities to take a holiday.

### **VOCATIONAL/EMPLOYMENT SERVICES**

#### *Workpath*

*Workpath* is a social support service which assists people who have returned to work after long-term unemployment. The programme is designed to counter the current outcome for this group where 1 in 4 returns to long-term social welfare dependency. RehabCare works closely with employers to ease the transition back to work for employees who have to adjust to new routines, time management, money management, benefits, entitlements and housing.

### *Training services*

RehabCare provides certified training courses in disability awareness and community care practice at various locations across the country.

### **HOUSING SERVICES**

#### *Supported accommodation services*

RehabCare provides supported housing and hostel accommodation for people with disabilities. Its Newgrove Housing Association operates a range of accommodation from high-level support to complete independence.

### **INDEPENDENCE SERVICES**

#### *Independent Living Community Services (ILCS)*

Independent Living Community Services (ILCS) is a joint venture company between RehabCare and the Center for Independent Living (CIL) which aims to promote equal rights and to provide services to assist people with disabilities to live independently. In particular, it operates a personal assistant (PA) service which is used by more than 200 people with significant physical disabilities countrywide. ILCS also provides administrative back-up to 26 Centers for Independent Living around the country, along with university-accredited training for PAs and personal assistance training for people with disabilities. ILCS has a separate entry in this guide.

### **NATIONAL REPRESENTATIVE COUNCIL (NRC)**

The National Representative Council (NRC) was established in 1997 to give clients within the NTDI a greater say in the operation of the services they use. It now has more than 2,100 paid-up members. The organisation liaises with NTDI management at local and national levels to ensure that issues of concern to its membership are raised and dealt with. It also represents its members' interests externally by raising issues with the Irish Council for People with Disabilities and various government departments.

Local NRC advisory committees, elected by the service users, operate in NTDI centres throughout the country. The NRC is also represented on the board of Rehab Council, the central policymaking body within the Rehab Group. The NRC is currently in discussion with a view to expanding its services to clients within RehabCare.

### **PROGRAMMES AND RESEARCH DEPARTMENT**

Rehab's Programmes and Research Department supports the various group divisions in monitoring, developing and improving service delivery. The department works to ensure that the group's mission and values are evident in all service activities. It is responsible for the development of appropriate policies and procedures, support for new service developments and the transfer of experience and expertise between service providers with the group. It is also concerned with the development of effective external partnerships, the evaluation of innovations, consultation with service users and the promotion and implementation of research.

The Programme and Research Department is currently involved in some benchmark projects, particularly an initiative to reduce the incidence of work-related accidents and illness called *Workforce Plus*. In consultation with University College Dublin (UCD), the Programmes and Research Department has developed a master's degree programme in disability management and a graduate diploma in social and vocational rehabilitation. It also facilitates key projects on the social and economic lives of people with disabilities through the Rehabilitation Research Foundation.

#### **REHAB FOUNDATION**

The Rehab Foundation acts as a catalyst for positive change through a diverse range of activities including publishing, advocacy, funding research, providing bursaries and scholarships and event management. It coordinates the group's communications and fundraising activities. It is also responsible for the voluntary structure of the organisation.

The Rehab Foundation publishes a number of award-winning, in-house (staff and service users) and disability sector magazines. The titles include *Rehab News*, a staff and service user magazine, *Insight*, the only publication to embrace the entire disability sector in Ireland, *Employers' Platform*, a specialist business-to-business magazine and *Recycling News*, a publication aimed mainly at schools.

Major ongoing fundraising events include the Rehab super draw, the RehabCare bear campaign which raises funds for respite services and for the Cooperation Africa project (this finances education projects in the South African township of Soweto) along with an annual sponsored international walk and weekly radio bingo on local radio stations.

The group's voluntary structure comprises more than 3,000 people on committees throughout the country.

#### **REHAB LOTTERIES**

Rehab Lotteries commenced trading in November 1987. Since then, it has raised just more than £20m for the Rehab Group and other not-for-profit organisations. The company's business is mainly based on scratch cards which are sold in 2,000 retail outlets throughout the country.

# **RIDING FOR THE DISABLED ASSOCIATION - IRELAND**

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Templecarrig Lower  
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Co. Wicklow

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Fax: (01) 2876503

Contact: Niamh Kingston

## **RIDING FOR THE DISABLED**

Participation in any sport gives a feeling of well-being and enjoyment. Riding provides a unique opportunity to be in close contact with horses and to develop postural, balance and muscular skills. It teaches patience and self-control and gives individuals a sense of accomplishment. It is usually undertaken outdoors and gives the benefit of exercise in the fresh air.

Group riding and trap driving provides opportunities for social development and formation of friendships. Competition gives people an opportunity to demonstrate their skills and to enjoy competition. In Ireland, trap driving for disabled people is becoming increasingly popular, with a number of competitions held in the year.

## **INTRODUCING RIDING FOR THE DISABLED ASSOCIATION - IRELAND**

Riding for the Disabled Association - Ireland was founded in 1968 to give riding opportunities to people with physical and learning disabilities and thereby improve their health and well-being. The activities

of the association are undertaken by a large number of volunteers, who give their professional expertise, the use of their riding establishments and their time, free of charge. In the past 10 years, the association has developed pony and trap driving groups. It has also introduced instructor assessment. During this time, the numbers availing of the association's services have increased significantly. The main concerns for Riding for the Disabled Association - Ireland include the ongoing search for suitable volunteers and the need to source funding to enable the association to develop.

## **MEMBERSHIP AND BOARD STRUCTURE**

Riding for the Disabled Association - Ireland comprises 83 groups in 14 geographical areas throughout the country, providing approximately 1,000 people with disabilities with riding opportunities, and involving about 800 instructors and helpers. Services are not provided to nonmembers.

The association is a company limited by guarantee. Its charity number is CHY: 6534. The council of Riding for the Disabled Association - Ireland has 26 members, including 14 area representatives from area committees, association officers and nominated members, (usually expert) who are elected annually by the council. The rotation for ordinary membership is every 2 years and the council meets approximately 6 times per year.

## **INCOME AND EXPENDITURE**

Riding for the Disabled Association - Ireland turns over approximately £20,000 annually. Most of this sum is raised through voluntary fundraising activities at local area level. Fundraising events include coffee mornings and annual walks. Riding for the Disabled



Association - Ireland obtains no EU or FAS CE funding. It obtains £1,000 per annum, through the Equestrian Federation of Ireland.

#### **STAFF**

Riding for the Disabled Association - Ireland has no paid staff, but relies on the voluntary work of about 800 people. These include the council members, the training committee, instructors and helpers. There are no staff wage costs. Riding for the Disabled Association - Ireland has no involvement with the CE programme. The volunteer programme is not costed.

#### *Training, monitoring and evaluation procedures*

Riding for the Disabled Association - Ireland operates induction, accredited training and other in-house training for instructors and helpers. The association has written safety procedures and internal reporting mechanisms. Riding and trap driving are under the supervision and advice of physiotherapists and with medical permission. Riding for the Disabled Association - Ireland has never undertaken an independent review of its services or organisation, but has ongoing internal reviews of all its activities.

#### **PREMISES**

Riding for the Disabled Association - Ireland uses existing riding schools for a few hours each week and rents meeting rooms as required.

## **SERVICES**

#### **INFORMATION SERVICES**

Riding for the Disabled Association - Ireland publishes an annual newsletter, circulated to participating riding schools, instructors and helpers.

#### **RECREATION SERVICES**

Riding for the Disabled Association - Ireland provides weekly riding and trap driving experience for up to 1,000 people with disabilities. Many of the riders are referred from special schools. Some of the riding groups within Riding for the Disabled Association - Ireland organise riding holidays for their disabled riders.

# ROYAL HOSPITAL DONNYBROOK

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Dublin 4

Tel: (01) 4972844  
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Manager: John Kennedy  
Medical director: Dr. Mary Deane

## **INTRODUCING THE ROYAL HOSPITAL DONNYBROOK**

The history of the Royal Hospital Donnybrook spans more than 250 years. The original Hospital for Incurables was established in 1743, was funded by the proceeds of charitable concerts in the city and provided services free of charge to people of all religions. On 7 January 1800, the hospital obtained its first royal charter from King George III and for some time the hospital was part-funded by a parliamentary grant, although charitable donation remained a vital component of the budget.

In more recent times, the hospital has developed a range of inpatient and outpatient services. These include elderly post-acute rehabilitation, both inpatient and in a day setting, respite placements and a unit for elderly confused people. It has also provided a sheltered housing complex for frail elderly people in the hospital grounds. A major capital development expansion is now in train, with a new hospital block to be built by the end of 2000.

## **MEMBERSHIP AND BOARD STRUCTURE**

The Royal Hospital Donnybrook is not a membership-based organisation. The hospital has 2 patrons, a board of management of 21 members, including 2 nominated by Dublin Corporation. The hospital also has a board of governors, which includes many hundreds of individuals who achieve this status through donation or through appointment. Some governors serve voluntarily on management, planning or fundraising committees. The hospital benefits from the fundraising activities of the Friends of the Royal Hospital.

## **INCOME AND EXPENDITURE**

In 1998, the hospital cost just over £7m to operate. Of this, approximately £6m was obtained directly from the Department of Health and Children and the remainder came from patient maintenance charges, payroll deductions, and sundry income. The hospital was in receipt of £206,240 in voluntary gifts and donations for 1998, equivalent to less than 3% of the annual expenditure. The Friends of the Royal Hospital are active in raising funds for capital development and research projects, using a wide range of methods.

### *Expenditure*

Pay accounted for expenditure of £5.2m. Other costs included food and catering fees of £346,000, maintenance and renovations of £275,000, cleaning and washing £240,000. Drugs and medicines cost the hospital approximately £152,000.

### **STAFF**

The Royal Hospital Donnybrook employs more than 200 staff members. Some work part-time, are job-sharing or sessional. The hospital administration is headed by a secretary manager. The hospital medical direction is undertaken by the medical officer. There are 11 ward sisters, including two night sisters, approximately 60 staff nurses, more than 40 enrolled nurses, about 22 attendants, 10 care assistants and more than 20 household staff and other grades such as gardener, porters and general services operatives. The hospital has participated in a FAS CE scheme since the late 1980s. In addition to this staff, the hospital has more than 100 volunteers who provide residents with regular visits, companionship, shopping trips and other expeditions.

### *CE scheme*

CE scheme workers run bingo and whist sessions, accompany patients to dental and other appointments, talk to patients in their wards and take patients to and from religious services. Suggestions have been put forward about an in-house training scheme for these workers.

### **PREMISES**

The hospital was established at Donnybrook in 1792. It occupied large buildings which have been extended over the centuries and which now require extensive and ongoing maintenance and repair. Additions to the main building have been added, notably the day hospital and the new unit for elderly confused people. In addition, the hospital has built sheltered housing units in the spacious hospital grounds.

## **SERVICES**

### **INFORMATION SERVICES**

The Royal Hospital Donnybrook produces informational brochures and leaflets about its activities. Individual departments provide relevant information to people attending the hospital, and their relatives. The social work department is active in informing patients and their relatives of the social benefits and entitlements.

### *Publications*

The hospital produces an annual report. It published a history of the hospital in 1993, to mark the 250<sup>th</sup> anniversary of its foundation. *The Royal Hospital Donnybrook - A heritage of caring*, written by Helen Burke of the Social Science Research Centre, in University College Dublin (UCD) is a detailed account of the hospital's past up to the year 1990.

### *Research*

The hospital has undertaken descriptive research projects on the hospital population. Individual departments may publish and/or present research on individuals and groups.

### **MEDICAL/NURSING AND THERAPEUTIC SERVICES**

The main role of the Royal Hospital Dublin is to provide long-term care for elderly people who are chronically sick or disabled. The number of long-stay patients is 190. Almost 70% of long stay patients are women and half of all patients are unmarried. Many of these people are very elderly: 40% were 80 years or older in 1990. They receive nursing care and where applicable the services of the chiropodist, occupational therapist, physiotherapist, speech and language therapist and medical social worker. Part of the remit of the Royal Hospital Donnybrook is the provision of palliative care.

### *Therapeutic services*

The Royal Hospital Donnybrook has 2 rehabilitation wards (34 beds). Inpatients receive nursing care and appropriate therapy services. In 1990, 181 patients received inpatient rehabilitation. There is also a day rehabilitation hospital and 89 people were regular attenders in 1990.

### **SUPPORT SERVICES**

Inpatients, outpatients and their families obtain ongoing support from nursing, care and therapy staff. The hospital also has a pastoral care staff.

### *Counselling services*

Social workers provide ongoing counselling for individuals and small groups in all areas of the hospital. Counselling services are also available to relatives of inpatients.

### *Psychology services*

The Royal Hospital Donnybrook employs a psychologist who undertakes psychometric assessment in the day hospital and rehabilitation wards. The role of the psychologist is to promote and maintain the mental health of patients and to assist them in coming to terms with their disability and their environment. Activities of the psychologist include the establishment of support groups for people with stroke and carers' support groups.

### *Respite services*

Some bed places in the rehabilitation wards are used for respite placements. People availing of this service receive nursing care and where applicable the services of the chiropodist, psychologist, occupational therapist, physiotherapist, speech and language therapist and medical social worker.

### *Visiting services*

Medical social work and therapy staff may undertake home visits when applicable.

### *Equipment purchase or loan*

Patients attending the day hospital may be provided with necessary equipment, aids and appliances.

**RECREATION SERVICES**

Recreation services are on offer to inpatients in the long-stay and rehabilitation units. These include daily outings, weekly sessions of bingo and whist and regular concerts.

**HOUSING SERVICES**

In 1991, the Royal Hospital Donnybrook established a housing association to achieve and manage a sheltered housing development of 29 units on the hospital grounds. The hospital obtained a capital grant from the Department of the Environment and the Eastern Health Board and Dublin Corporation have been involved in ensuring adequate support services for residents.

# ST. GABRIEL'S SCHOOL AND CENTRE

Address: Crabtree House  
Springfield drive  
Dooradoyle  
Limerick

Tel: (061) 302733  
Fax: (061) 302734

School principal: Kathryn O'Connor  
Centre manager: Miss Crabtree

## INTRODUCING ST. GABRIEL'S SCHOOL AND CENTRE

The centre was founded in 1961 for children with all types of disabilities by Arthur Crabtree, a retired local businessman, as a voluntary response to perceived local and regional needs. A school for pupils with physical disabilities was established in 1978 and was recognised by the (then) Department of Education. A new purpose-built school and therapy centre, including an outpatients' department opened in Dooradoyle in December 1996. In the past 5 years, teacher and therapy staffing levels have doubled. The aim of the school and centre is to provide a quality service for children and young adults with multiple disabilities.

The main concerns for St. Gabriel's School and Centre are the lack of secure and adequate State funding to meet staffing requirements and the lack of capital finance to expand facilities. St. Gabriel's also points to the lengthy delays experienced in obtaining aids and appliances which are required by the children immediately and of necessity.

## MEMBERSHIP AND BOARD STRUCTURE

St. Gabriel's School and Centre is not membership-based. Services are provided to people with a physical disability or with multiple disabilities living in the Mid Western Health Board region. The school is under the aegis of the Department of Education and Science. The board of management consists of 8 members, with a 3-yearly rotation and with at least 6 meetings per year. The therapy centre is managed by a voluntary committee with 8 members from business, professional and medical interests. Membership rotates annually and the board meets approximately 6 times per annum.

## EDUCATING YOUNG PEOPLE WITH MULTIPLE DISABILITIES

The provision of a comprehensive education service for children and young people with multiple disabilities requires a flexible, interdisciplinary approach. At present, staff in many special schools are hindered by the gaps in the existing services. Some teachers in special schools do not have the benefit of input from specialist clinical or educational psychologists. This can pose significant problems when seeking to identify and respond to individual children's learning needs.

Families with children with special needs may require special financial or other support. In some instances, families may require specialised counselling services. Teaching staff can sometimes be the main direct contact for families with a child with special needs and yet may not have the time or expertise to help families in distress.

Changes in family patterns affect the lives of all children. Some children with special needs come from lone parent families, from large families, from families living in poverty. Addressing their educational needs means responding to their personal and family circumstances.

## **INCOME AND EXPENDITURE**

### *School*

The Department of Education and Science provides core staff funding for 8 teachers and 4 classroom assistants and capitation grants for pupils at the school. The school also benefits from a funding input from St. Gabriel's management executive which provides funding for 2 classroom assistants. The school has a large FAS CE scheme.

### *Centre*

The annual turnover is approximately £300,000. Staff costs, not including the school, amount to £250,000 per annum. The Mid Western Health Board provides 70% of ongoing funding of the therapy centre. The remaining funds are sourced through charitable donations. The main fundraising methods include church gate collections, raffles, coffee mornings and other events, run by volunteers. A CE scheme is in operation and is valued at £122,000 per annum.

## **STAFF**

The therapy staffing arrangements of the school and centre are closely intertwined. Individual staff provide services to both the school and the centre, but their full-time salaries may be covered by a variety of financial sources. In addition, the CE scheme operates through the school and centre in a delineated manner. Because the school and centre are located in the same building, certain activities including initial reception, cleaning, care-taking etc. are effectively shared.

### *School*

The school employs 14 staff members, 8 qualified teachers and 4 classroom assistants, all paid by Department of Education and Science. The school has 2 additional classroom assistants paid for by the executive committee, 2 part-time specialist teachers (one in physical education and one in home economics) both paid by Department of Education and Science, a qualified paediatric nurse and 2 assistants paid for directly by the school and centre executive body. The school and centre share equally the time of 2 full-time occupational therapists and 2 full-time physiotherapists. The school also has significant level of CE staffing, including 5 CE workers employed as classroom assistants, 2 cleaners, a housekeeper, a part-time receptionist, a groundskeeper and caretakers. The school can call on 4 volunteers, who provide additional classroom assistance.

### *Centre*

The centre has a medical director and a part-time centre manager. In addition to shared staff (see above), the centre employs 2 full-time physiotherapists, an occupational therapist and a speech and language therapist, a full-time occupational therapy assistant and a part-time physiotherapy assistant. The centre has 2 part-time secretary receptionists and a cleaner.

### *CE scheme*

In all, the school and centre have 19 CE workers and a CE scheme supervisor. The CE scheme is essential to the running of both the school and centre. A total of 20% of CE workers obtained mainstream employment in 1998. Problems encountered with the CE scheme include ongoing difficulties in recruitment and retention and low levels of literacy among many of the CE staff, which limits their capacity to assist in the classroom.

### *Training, monitoring and evaluation procedures*

The CE workers are provided with induction through the FAS programme. St Gabriel's teaching and therapy staff attend appropriate in-service training courses. St. Gabriel's does not operate accredited training programmes for staff, CE workers or volunteers, but is interested to do so. It operates in-house induction and training for all categories of staff and has ongoing input into student teacher, child care work and therapist training. It does not have a written volunteer policy.

St. Gabriel's has written safety, complaints and internal reporting mechanisms. The school is examined by the Department of Education and Science inspectorate, submits school plans and conforms, in all ways, to the requirements for State schools. Clinical supervision of the centre's therapy staff is undertaken by the medical director.

### **PREMISES**

St. Gabriel's is a purpose-built, fully accessible school and therapy centre, with administration offices, classrooms, resource teaching rooms and a pupils' canteen. Each of the 7 classes has access to at least 2 computers. The centre comprises therapy offices and rooms, a motor/sensory room, a physiotherapy and gym, a consultant's rooms and a paediatric nursing unit. The centre also has a computer dedicated to therapy programmes. There is an outdoor playground with wheelchair facilities.

## **SERVICES**

### **EDUCATIONAL SERVICES**

St. Gabriel's School is a Department of Education and Science-funded and recognised school for children with physical and learning disabilities living in the mid-western region. It provides a modified primary and post primary curriculum. The 45 pupils are aged from 4 -18 years. Each pupil has an individual education programme, drawn up in consultation with teaching and therapeutic staff. The school has ongoing and developing links with mainstream schools, in particular, a direct link with the adjacent St. Paul's primary school and with post-primary classes in local mainstream schools. Children attending St. Gabriel's sometimes move to or from mainstream schools. Children attending St. Gabriel's school are eligible for school transport services, in line with the standard guidelines of the Department of Education and Science.

### *Plans for school*

St. Gabriel's School wishes to avail of professional psychological/counselling services for children attending the school. At present, the Department of Education and Science national psychological service is not available to pupils in special schools.

### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

#### *Medical services*

The centre operates under a medical director who provides appropriate medical diagnostic services and refers children to appropriate therapeutic services.



### *Nursing services*

The school operates a paediatric nursing unit staffed by a paediatric nurse and 2 assistants. This service ensures emergency intervention and provides ongoing nursing and care assistance, e.g. catheter regulation. Children attending the centre can also receive necessary nursing assistance. School and centre staff maintain contacts with the family section of the Mid Western Health Board, in particular the counselling nurses.

### *Therapeutic services*

St. Gabriel's provides an occupational therapy, physiotherapy and speech and language therapy service to children attending St. Gabriel's school. These therapy services are also available to children with a physical disability on an outpatient basis. The waiting list for appointments is about 6-8 weeks. Approximately 150 children are currently in receipt of services annually. Transport to and from the clinics can be arranged through the health board. All therapy staff provide an outreach service to pupils who live far from the school, during the school summer holiday period.

### *Plans for centre*

From November 1999, St. Gabriel's Centre will have its own specially adapted bus and will employ a driver, through the CE scheme, to provide a dedicated transport service. St. Gabriel's Centre hopes to expand its service to include a purpose-built seating clinic and a hydrotherapy pool with appropriately qualified staff.

## **SUPPORT SERVICES**

All therapy and paediatric nursing staff carry out home visits to help develop home programmes, to liaise with the staff of the school and centre, to assess for aids and appliances and to provide advice with housing adaptations. The centre hopes to obtain funding to employ a qualified psychologist/ counsellor.

### *Equipment purchase or loan*

The centre lends special equipment, for assessment purposes, or while waiting for delivery of equivalent aids from the Mid Western Health Board. The main items lent include standers, bathroom aids, hoists, shower trolleys and powered wheelchairs. The centre also supplies augmentative communication aids, many of which cost £7,000 -£10,000 and are essential to enable individual children to benefit from the education provided.

## **ADVOCACY SERVICES**

St. Gabriel's School and Centre staff and management seek to engage in constructive dialogue with the relevant statutory agencies, both national and regional. St. Gabriel's lobbies the Mid Western Health Board for improvements in funding, in staffing levels and for provision of aids and appliances required by individual children.

*Links with other organisations*

St. Gabriel's has ongoing contact with the Central Remedial Clinic (CRC) in Dublin, where many of the pupils and centre clients attend for review, for specialised fittings and other services. It also has direct contacts with Cerebral Palsy Ireland (CPI), Mungret Limerick, Irish Wheelchair Association (IWA), with the Brothers of Charity services at Bawnmore, with the regional RehabCare service and with the regional offices of the National Rehabilitation Board (NRB) and the National Training and Development Institute (NTDI).

# ST. MARY'S HOSPITAL AND RESIDENTIAL SCHOOL

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**ST. MARY'S HOSPITAL AND RESIDENTIAL SCHOOL  
BALDOYLE**

**The overall aim of St. Mary's is to provide a  
happy and stimulating home from home  
environment for all the children in their care.**

## **INTRODUCING ST. MARY'S HOSPITAL AND RESIDENTIAL SCHOOL**

St. Mary's Hospital and Residential School (St. Mary's), run by the Sisters of Charity religious order, was founded in 1954 during the outbreak of poliomyelitis as a rehabilitative centre associated with Cappagh Hospital. It now offers full-time residential, day and respite services to children with primary physical and multiple disabilities from all over the country. In all, 60 children live at St. Mary's Hospital and Residential School. The aim of the hospital and school is to ensure a suitable environment to enable each child to reach his or her full potential physically, emotionally, spiritually, socially and intellectually. The hospital has submitted a development plan to the Department of Health and Children and awaits approval for an extension to its facilities.

## **MEMBERSHIP AND BOARD STRUCTURE**

St. Mary's Hospital and Residential School is not a membership-based organisation. The board of management comprises 10 members who come from professional, managerial and medical backgrounds. The board meets 6 times per annum.

## **INCOME AND EXPENDITURE**

The total annual costs for St. Mary's Hospital are in the region of £1.8m per annum. Most of this is provided through State funding *via* a direct grant from the Department of Health and Children. From 1.3.2000, the Eastern Health Board will take over the direct funding of the hospital. The school is funded by the Department of Education and Science. About £10,000 - £15,000 is obtained from charitable sources, principally through fundraising (golf classic) and voluntary contributions (from local organisations). These are used to purchase specialised equipment, including electric wheelchairs and speech synthesisers and for extra activities.

## **STAFF**

Approximately 120 people are employed in St. Mary's Hospital and Residential School at any time. This includes a director of services, 15 staff nurses, 2 part-time doctors, 2 occupational therapists, 1 full time and 2 part time physiotherapists, 1 part-time speech and language therapist, 1 psychologist, 2 part-time social workers, 1 pastoral care worker and 31 care

workers. The school staff consists of a principal, 6 teachers and 8 classroom assistants. St. Mary's Hospital and Residential School has no involvement with the CE programme.

#### *Training, monitoring and evaluation procedures*

St. Mary's Hospital and Residential School has written safety, complaints and internal reporting mechanisms. In 1996, a study group was set up to evaluate the services offered in St. Mary's. As a result, recommendations were made and implemented in relation to future plans for St. Mary's.

#### **PREMISES**

St. Mary's Hospital and Residential School is a large building, fully accessible with dormitory ward and single bedroom accommodation available. All bedded units have fully accessible bathroom facilities. The hospital provides overnight facilities for parents travelling long distances. Meeting rooms are available for staff or parents and their children.

### **SERVICES**

#### **INFORMATION SERVICES**

St. Mary's Hospital and Residential School produces a brochure outlining its many hospital and school services. It holds parents' days to encourage parents to observe the activities of the children. St. Mary's has held open days to enable the general public to visit the hospital and school.

Parents and the child always visit the centre before placing a child. This is an opportunity for them to see St. Mary's, meet the staff and the other children and to discuss their expectations and concerns. It also allows key members of the staff to meet with the child to carry out initial assessment for the child attending on a trial basis.

#### **EDUCATION SERVICES**

##### *Developmental and educational centre (DEC)*

The DEC was established in 1997 to cater for 6 preschool children, resident and day pupils. Each child receives substantial personal attention within a sensory programme designed to stimulate the child in all areas of development. Each child's progress is reviewed monthly and parents are encouraged to take an active role in the DEC.

##### *Special primary school*

St. Mary's Hospital and Residential School includes a coeducational special national school, funded directly by the Department of Education and Science. It caters for 36 - 40 children between the ages of 3-18 years. A small number of these children are day pupils.

Teachers are qualified and experienced in special education. Each child has an individual education programme within a broad and varied curriculum including language and literacy, mathematics, history and geography, computer skills, gardening and nature study, social and independence skills, physical education, sport and leisure, music and singing, drama, art,

cookery and religious instruction. Some pupils are prepared for aspects of the National Council for Vocational Awards (NCVA) certificates.

Junior pupils and pupils with particular needs follow specialised developmental programmes which include appropriate stimulation in a comprehensive multi sensory curriculum. Activities within this specialised programme include integrated play, movement, music and massage. Special emphasis is placed on speech and language development.

#### *Children in residence in St. Mary's attending school in the community*

Over the years, a number of the children and young people who have lived in St. Mary's have attended community mainstream secondary schools. For these children, St. Mary's has attempted to provide the necessary supports and encouragement to complete their secondary education, including organising and financing grinds.

### **MEDICAL/ NURSING /THERAPEUTIC SERVICES**

#### *Medical services*

2 doctors attend St. Mary's. They provide regular reviews of the general health of all of the children, including an ongoing vaccination programme, relevant medical intervention, supervise the transfer of a child to hospital when necessary and to liaise with medical and surgical consultants. The hospital has 24-hour emergency on-call medical cover.

#### *Nursing services*

Within the hospital, there are 8 family units. Each unit caters for 10 children and includes facilities for respite placements. Each unit is staffed by 2 staff nurses and a number of care staff. Nursing staff assist the children in activities of daily living, provide specialist feeding assistance, accompany the child to appointments outside the hospital, help and advise parents on matters in relation to the care of their child and work in liaison with paramedical and teaching staff.

#### *Palliative services*

St. Mary's Hospital and Residential School provide a palliative medical, nursing and support service (social work and counselling) for children who are dying and for their families.

#### *Therapy/rehabilitation services*

##### *Physiotherapy*

Each child is allocated his/her own physiotherapist. The physiotherapist provides assessment and review, gives therapy as necessary, including hydrotherapy in the hospital's swimming pool, and recommends and organises the provision of walking aids, splinting and specialised footwear. The physiotherapy staff also advise and train other staff in correct lifting and handling techniques.

##### *Occupational therapy*

The role of the occupational therapist is to assess and maximise each child's level of independence in areas such as activities of daily living, memory, concentration and perception. The occupational therapy staff assess each child's requirements for a wheelchair and arrange for their supply. This service is part of a seating clinic. The occupational therapy staff organise the provision of aids, appliances and specialised equipment. Occupational therapy staff at St.

Mary's Hospital and Residential School liaise with community-based occupational therapists to advise on structural and other adaptations to the child's home.

#### *Speech and language therapy*

The speech and language therapist assess each child's communication capacity and develops a personalised communication programme, which may focus on building speech skills or may adopt one of a number of alternative and/or augmentative communication systems, such as a computer with voice output, personalised communication books with pictures or use of face and body gestures.

### **SUPPORT SERVICES**

St. Mary's seeks to provide support to each child at the hospital and school and to their parents. Although the hospital does not operate a formal helpline, staff are available at all times for the families of the children in their care. Staff also seek to ensure that support services are available locally to families and to children when they leave the hospital.

#### *Psychology and counselling services*

In addition to the assessment of intellectual development and provision of recommendations in relation to education, the psychologist provides a counselling and therapeutic service to meet the needs of the children in the hospital. The psychologist also works with other professionals in the hospital to ensure appropriate socialisation for the children.

#### *Social work services*

The main role of the social worker at St. Mary's Hospital and Residential School is to establish and maintain the link between the young person, his or her family and the hospital and school. The social worker also seeks to establish links with agencies in the community to facilitate reintegration of the child into locally provided services when they leave the hospital and school. Social workers provide parents with support, undertake home visits and encourage parents to become involved in support groups which are held at the hospital. The social worker also meets with the children and participates in the personal development aspects of the school curriculum.

#### *Respite services*

A residential respite service is available. It caters for approximately 25 children per annum, usually in the age range 2-18 years. The length of the respite break varies, depending on the needs of the particular family. During the respite break, some of the children continue to attend their own school and are transported from St. Mary's each day. Others attend school at St. Mary's and participate fully in the life of the hospital. St. Mary's has submitted plans for an extension of its respite unit and awaits approval for this development.

#### *Equipment purchase or loan*

Equipment for children is supplied either directly by St. Mary's or in liaison with the relevant health board for use by the child at home.

### **RECREATION SERVICES**

Recreation is part of the national educational curriculum and St. Mary's School provides opportunities to all children attending their educational service. Sport is also available to the children 2 evenings per week. In addition, extra curricular sport and leisure activities are organised by the hospital and school staff. These include swimming in the hospital pool, riding and daily and weekly outings. Children are encouraged to become involved in sporting competitions on a national basis with other special schools. In February 2000, the hospital intends to open a jacuzzi for the use of the children.

### *Holidays*

For the children who are in full-time residence in the hospital, holidays away during the year include a week long holiday in July and 5-day holiday in February and October. The children have been to Cork, Galway, Waterford, Leitrim, Longford, Laois, Meath and Westmeath. St. Mary's Hospital and Residential School encourages and enables children to take holiday opportunities with voluntary organisations.

### **INDEPENDENCE SERVICES**

St. Mary's Hospital and Residential School seeks to encourage maximal self-reliance and independence for all young people in the hospital and school. Part of the curriculum followed by pupils at the school includes an interdisciplinary personal development programme, where pupils work with 2 staff members in groups on issues such as social personal and health education. This programme incorporates the *Stay Safe* and the relationships and sexuality programmes of the Department of Education and Science.

### **ADVOCACY SERVICES**

The staff members in St. Mary's endeavour to act as advocates for the children in their care. The hospital has ongoing contact with the Department of Health and Children, seeking to maintain and improve the standards of service to the children. Hospital staff also have ongoing contact with health board officials throughout the country in relation to necessary equipment for children. Staff members have had contact with local authorities in relation to housing adaptations for children leaving the hospital.

# SCHIZOPHRENIA IRELAND

## LUCIA FOUNDATION

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E-mail: schizi@iol.ie  
Website: www.iol.ie/lucia

Director: Orla O'Neill

Cork office 4 Penrose Wharf  
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### INTRODUCING

#### SCHIZOPHRENIA IRELAND

Schizophrenia Ireland was founded in 1975 to address the information and support needs for caregivers of people with schizophrenia. It is now the national non-governmental organisation concerned with promoting the interests and

articulating the needs of people who have schizophrenia and their families. Services provided include support groups for people with schizophrenia and for caregivers throughout the country, a national telephone helpline, employment programmes, a counselling service, training courses for caregivers, lobbying/advocacy and public awareness-raising activities.

Schizophrenia Ireland is dedicated to upholding the rights and needs of everyone affected by schizophrenia and related illnesses through the promotion and provision of high-quality services and to working to ensure the continual enhancement of the quality of life of the people it serves. Significant developments for the organisation include the establishment in 1993 of *Worklink* (in Dublin and Donegal) – a training/supported employment programme. Schizophrenia Ireland opened its new headquarters in Blessington Street and established its telephone helpline in 1997. The organisation opened an office in Cork in 1999.

Schizophrenia Ireland now wishes to consolidate existing services and to introduce quality assurance mechanisms. It also wishes to develop the voluntary management structure of

### SCHIZOPHRENIA

Irish people generally know very little about schizophrenia and often hold wrong views and opinions about it. Schizophrenia is very common - about 1 in every 100 people have the brain condition. This means that about 35,000 Irish people are affected.

Schizophrenia is a serious disturbance of thought, perception, emotion and drive. It usually begins in early adult life. Early symptoms include withdrawal, confused thinking and blunted or inappropriate emotions. People with the condition can be extremely frightened by what is happening to them. Schizophrenia does not mean that the person has a split personality. It is not inherited, although some people seem to have a genetic predisposition to it.

The cause is unknown, but it is probably related to chemical imbalances in the brain. Contrary to popular, and now outdated, belief, it is not caused by family pressures.

It is treated with drugs and with appropriate therapy programmes. About 1 in every 3 people with schizophrenia have productive lives in the community. People with schizophrenia, like everyone else, benefit from social support and acceptance.



organisation. Its concerns include securing funding for the future and recruiting staff regionally to enhance support for groups.

#### **MEMBERSHIP AND BOARD STRUCTURE**

Schizophrenia Ireland has a national membership of 413. The organisation has Phrenz groups for people with schizophrenia in Clare (Ennis), Cork, Dublin (Blessington Street, Kilmacud, Ballyfermot, Artane), Galway and Longford. There is a branch network of carers groups in Clare (Ennis), Cork (Cork city), Donegal (Letterkenny, Inishowen, Killybegs, Buncrana), Dublin (Vergemount, St. James, Whitehall, Artane, Swords, Cluain Mhuire, Ballyfermot, Tallaght), Galway (Galway city), Kerry (Tralee), Kildare (Naas), Laois (Portlaoise), Leitrim (Carrick-on-Shannon), Limerick (city), Longford (Longford town), Mayo (Castlebar), Sligo (Sligo town, Easkey), Tipperary (Thurles), Waterford (Waterford city), Wexford (Wexford town). Services are provided to nonmembers.

The organisation is a company limited by guarantee. Its charity number is CHY: 6380. The board comprises 17 directors with members elected at annual general meeting (AGM) from the general membership. The board currently includes 11 carers/relatives, 3 people with schizophrenia and 3 mental health professionals. The board rotation involves the 3 longest-serving members stepping down at the AGM. They are eligible for reelection. The chair is elected annually for a period of up to 3 years. The president is appointed for a period of 2 years for a maximum of 2 consecutive terms. Officers are elected annually for a period of up to 4 years, after which they step down for at least one year. The board meet 6 times per annum.

#### **INCOME AND EXPENDITURE**

For 1998, Schizophrenia Ireland had an income of £784,892. It received £408,896 from the European Social Fund (ESF), £298,400 from State sources and £75,627 from charitable donations. Most income comes from EU or statutory sources. Little fundraising is undertaken due to the social stigma of mental illness in Ireland. The 1998 expenditure left a surplus for the year of £12,065. Total staff wage costs were £469,330. Administration costs were £88,000 and rent and mortgage interest cost £52,000.

#### **STAFF**

The total number of directly paid staff in the organisation is 18, not including sessional staff. There are also 7 CE workers. All staff are involved in front-line services and all are suitably qualified. The total number of volunteers is 12.

#### *CE scheme*

During the past year, 3 of Schizophrenia Ireland's CE scheme staff were placed in permanent employment within the organisation. One person left the scheme to pursue other CE scheme employment. One person left the scheme due to illness. Schizophrenia Ireland has found that the majority of CE workers are not interested in pursuing a career as a social service professional.

### *Training, monitoring and evaluation procedures*

Schizophrenia Ireland does not operate any accredited training programmes for staff, CE workers or volunteers. It provides in-house induction training for all staff and volunteers. It also provides in-house training in committee skills, computer training and health & safety training as needed and it trains volunteers in listening skills. The organisation has written safety procedures and internal reporting mechanisms. It undertook an independent organisational evaluation in 1997.

### **PREMISES**

The national office is located in one (owned) building. The Dublin employment programme is located in a neighbouring (owned) building with 2 general training rooms, a computer training room and a small meeting room. The Cork regional office is rented. Library facilities exist at the national office (open 9 am-5 pm) and at the Cork regional office, (open 9 am-5 pm.). There is no disabled access at any of the premises, apart from the regional office on the ground floor. Hygiene facilities are of adequate standard for the provision of training programmes for the client group.

### *Computerisation*

The national office has LAN with a dedicated server. The employment programme has a dedicated computer training room with 10 computers. Offsite premises have PC's, some in peer-to-peer LAN's. All sites have one PC connected to the internet. Each site has an e-mail account.

## **SERVICES**

### **INFORMATION SERVICES**

Schizophrenia Ireland provides general information leaflets on support services offered by the organisation, as well as general information pertaining to the condition. It also has an information guide (book) which gives a detailed description of schizophrenia, its effects on everyday life and gives common sense advice to people with the condition and their families. Schizophrenia Ireland produces a quarterly newsletter and an annual report. It organises roadshow seminars nationally which explore issues of concern for people with schizophrenia and their carers. The organisation operates a national telephone helpline, 5 days per week, 2 hours per day, which provides information and support. The library at the national office in Dublin has a range of books and videotapes. Schizophrenia Ireland has a list of books and videotapes for sale/loan. It also has a website: : [www.iol.ie/lucia](http://www.iol.ie/lucia)

### *Public awareness*

Schizophrenia Ireland runs a national awareness day, Lucia Day, 26<sup>th</sup> July. It hosts a biennial conference on schizophrenia for people with the condition, carers and professionals.

## **SUPPORT SERVICES**

### *Personal and family support services*

Branch support groups for people with schizophrenia and for their families and caregivers meet weekly or monthly. Schizophrenia Ireland runs family support courses, specifically a weekend course to provide caregivers the skills to cope with schizophrenia. The organisation plans to develop family support in collaboration with health boards.

### *Helpline*

Schizophrenia Ireland operates a national telephone helpline at 1890 621631.

### *Counselling services*

Schizophrenia Ireland provides professional personal, group and family counselling at its Dublin office.

### *Respite services*

Schizophrenia Ireland provides one respite break per annum for people with schizophrenia.

### **SCHIZOPHRENIA HELPLINE 1890 621 631**

The Schizophrenia Helpline aims to provide information and support for anyone whose life is affected by schizophrenia. It is a nationwide service and is staffed by a team of trained volunteers who listen in a non-judgmental way. The service is confidential and calls are charged at local call rates. The opening times are:

Monday	1.30 - 3.30 pm
Tuesday	5.30 - 7.30 pm
Wednesday	3.00 - 5.00pm
Thursday	10. 00 am - 12. noon
Friday	1.30 -3.30 pm

## **RECREATION SERVICES**

The organisation holds 2 social clubs weekly in Dublin, for people with schizophrenia.

## **VOCATIONAL/EMPLOYMENT SERVICES**

In Dublin and Donegal, Schizophrenia Ireland operates a work programme called *Worklink*. This aims to assist people who have schizophrenia to find and retain employment. There is an initial vocational assessment for access to this programme. Staff often refer clients to other programmes which are deemed to be more appropriate. The programme comprises various modules to develop skills for clients to access open employment. Job coaches place clients in jobs, (either work placement or paid jobs) and provide follow-up support services. Schizophrenia Ireland plans to develop a job's club in liaison with FAS. It also wishes to develop the vocational and employment support service with health board involvement.

## **ADVOCACY SERVICES**

Schizophrenia Ireland has a written advocacy statement. It sets out the personal and social rights and legitimate expectations of people with schizophrenia, their families and caregivers. It lobbies government departments, particularly the Department of Health and Children, and the health boards on issues or for funding as the need arises. Regional development officers, (currently in the EHB and SHB regions) are developing an advocacy service. The organisation wishes to extend its advocacy service nationally under the auspices of Disability Federation of Ireland (DFI). All of Schizophrenia Ireland's services have an ethos of empowerment.

## **SHANNON COMMUNITY WORKSHOPS LTD.**

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Contact: Alex Good

### **INTRODUCING SHANNON COMMUNITY WORKSHOPS LTD.**

The workshops were founded in 1967 as a national prototype for reintegrating people with mental illness into society. In the last decade, the Shannon Community Workshops Ltd. has emerged as a replicable national model and the management now seeks to develop the facility into a European model of excellence. The workshops currently provide real work for 50 people in an inclusive sheltered environment.

The major problems confronting Shannon Community Workshops Ltd. include ongoing technical production and raw material sourcing difficulties. Social prejudice against people with mental difficulties remains a real problem in selling the concept behind the workshops. The workshops' management is also concerned to ensure the recruitment of new workers.

### **MEMBERSHIP AND BOARD STRUCTURE**

Shannon Community Workshops Ltd. is not a membership-based organisation and services are provided only to those people working in the workshops. The board of management has 8 members, with limited rotation. On average the board meets 8 times per year.

### **INCOME AND EXPENDITURE**

The annual turnover for the company is in the order of £650,000. Most of this (approximately £400,000) comes from the sale of the product of the workshops, trading as Irish Country Pottery. The balance comes from the retail shop and bistro. The workshops receive no European Union funding. About £50,000 per annum comes from the Mid Western Health Board as Section 22 funding, and the FAS contribution is valued at £130,000. Donations amount to about £5,000. The company is legally prohibited from fundraising.

#### *Expenditure*

The total wage costs are £329,000, of which FAS CE represents £95,316. Substantial sums are spent on purchases for the retail operation, with 26% spent on raw materials in pottery production. The company pays rent for its 18,000 square foot facility. Extensive, ongoing production research is carried out at a cost of about £45,000 per annum

## **STAFF**

There are 18 directly paid staff, of whom 3 are administrative and 10 have necessary or relevant qualifications. Up to 16 people may be on placement in the workshops through the community employment scheme (CE).

### *CE scheme*

The CE scheme is important for the workshops. The placement rate in open employment or CE workers is about 70%. The workshops have no volunteers.

### *Training, monitoring and evaluation procedures*

The workshops have formal induction programmes for staff and CE workers. CE workers obtain ongoing training in work related skills. The workshop's management is in discussion with FAS on the development of a pilot scheme to introduce direct employment training. The workshops have stated safety, complaints and internal reporting procedures.

In 1993, Shannon Community Workshops undertook a complete review of its activities. In 1998, it assisted Disabled People of Clare (DPOC) to complete a review of entitlements and service provision.

## **PREMISES**

Shannon Community Workshops Ltd. is located in a 18.000 sq. ft. unit, with adequate access. The entire operation of the workshops is computerised including training facilities using 6 computers. There are 2 meeting rooms.

# **SERVICES**

## **INFORMATION SERVICES**

### *To workers*

Shannon Community Workshops Ltd. provides an extensive information and advice service to their workers. Information and advice are available on independent living, housing, entitlements, community services, holidays etc. Shannon Community Workshops Ltd. produces a newsletter about its activities.

## **SUPPORT SERVICES**

The workshops' environment provides ongoing support for workers. A support worker (an employee with a social work background) provides ongoing personal, group and family support and counselling.

### *Financial support*

Workers are paid a weekly top-up production bonus which is added to their Disability Allowance entitlements. They also earn a profit-sharing bonus, 3 times a year.

## **RECREATION SERVICES**

In the past, the Shannon Community Workshops Ltd. had a social club for employees. This was disbanded because the workers preferred to be involved in generic community activities. All workers have access to the facilities at the Shannon leisure centre, free of charge.

### *Holidays*

The workshops operate a savings scheme to assist workers to save for holidays. The support worker assists workers in making holiday arrangements if necessary.

### *Other recreational involvement*

Shannon Community Workshops Ltd. sponsors and supports the Disabled People of Clare's (DPOC's) theatre activities. Workers are encouraged to pursue interests through integrated night classes and costs incurred are paid for by the company.

## **HOUSING SERVICES**

Shannon Community Workshops Ltd. provides a 5-day hostel for 20 of its workers. This hostel has minimal support levels and workers availing of it are essentially independent. A husband and wife team of proprietors/managers live in the hostel.

### *Emergency housing assistance*

The hostel accommodation is used as an emergency housing service and as a backup to families in a variety of crises and other circumstances.

## **EMPLOYMENT SERVICES**

Shannon Community Workshops Ltd.'s main aim is to provide ongoing employment in a high-tech industry for people with mental illness.

### *Planned training services*

As part of the overall service, literacy training is available. The workshops are in the process of setting up a computer training facility to introduce computer use to workers with the assistance of a volunteer trainer.

# SPINAL INJURIES ACTION ASSOCIATION

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E-mail: [siaairl@tinet.ie](mailto:siaairl@tinet.ie)

Staff: Colm Whooley  
Eugene Cahill

Support  
coordinator: Joan Carthy

## INTRODUCING THE SPINAL INJURIES ACTION ASSOCIATION

The Spinal Injuries Action Association (SIAA) was founded in 1993 to provide a welfare/resource centre and support services for people with spinal cord injuries and their families. It has contacts with other similar organisations in Ireland, Europe and the USA.

It opened its office in 1995 and since that time has had a productive relationship with FAS which has allowed it to develop its services, particularly its national outreach support service. It has also developed a venture sports' expertise which it uses to challenge and motivate people with spinal injury to reach their potential.

The SIAA campaigns for improvements in the employment, training, housing, social welfare, health service and transport provision to its members. It seeks the change of existing medical card rules which discourage people with spinal injury from returning to employment. The SIAA highlights the variability of services received by its members from the different regional health boards, particularly in relation to the standard of wheelchair provision and the availability of occupational therapists nationally.

## SPINAL INJURY

Spinal injury is the term used for any acquired (i.e not from birth) total or partial severing or injury to the spinal cord. The human spine is conceived of in terms of cervical (neck), thoracic (chest) and lumbar (lower back) regions. The precise level at which the injury occurs along the spine, and the extent of the injury, give rise to inevitable but variable effects. The person with a spinal injury may have paralysis or significant difficulty of the body movement controlled by the spinal nerves below the point of injury. They may also have loss of sensation below the point of injury.

Spinal injury affects approximately 50 people every year in Ireland. Most of these people will become wheelchair users. Approximately 11,000 Irish people's lives are affected by the consequences of a spinal injury to a member of their family.

Immediately after a spinal injury a person may need emergency assistance. This is typically followed by an extended period of inpatient rehabilitation. The main centre for spinal injury rehabilitation is at the National Medical Rehabilitation Centre at Rochestown Avenue in Dun Laoghaire, Co. Dublin. When rehabilitation ends, the person with a spinal injury typically has no continued access to support or other services.

Some people with spinal injury rebuild the lives they had before the injury. For many others, however, this proves impossible. Their lives are shattered by the spinal injury - About 80% become long-term unemployed. Many experience significant financial difficulties and/or family problems. They may be severely restricted by lack of accessible transport and by lack of local opportunities for vocational training. Many people in these circumstances lose their sense of self-worth and become chronically depressed.

## **MEMBERSHIP AND BOARD STRUCTURE**

The SIAA has an active membership of about 1,200. It has no formal branch structure, but has regional voluntary officers who coordinate the association's activities in each area. The SIAA is a company limited by guarantee. Its charity number is CHY: 11535. The SIAA has a board of 10 members, 9 of whom are members with spinal injury and 1 patron. The lower age limit for board membership is 16 years. No upper age limit is in operation. The board meets 8 times per year. The rotation is annual.

## **INCOME AND EXPENDITURE**

For 1998, the SIAA estimates it received £79,000. Of this £11,000 was obtained through the National Rehabilitation Board (NRB). A total of £41,000 came from the CE programme and the employment support scheme, £10,000 was received from the lottery fund through the Department of Health and Children and the remainder came from other sources including voluntary donations and subscriptions. The SIAA received no funds from any health board source. The SIAA uses every possible ongoing means at its disposal, given its limited human and other resources, to raise funds from any legitimate source.

### *Expenditure*

In 1998, the SIAA estimates it spent approximately £90,000, excluding the CE-related expenditure. Of this £64,000 was spent on wages and salaries.

## **STAFF**

The SIAA has a total of 9 staff members, 3 of whom are full-time and the remaining 6 are part-time CE workers. In total, 2 of the staff members are administrative and 1 is a full-time support coordinator. All have relevant skills. The SIAA can call on about 30 volunteers who assist with the venture sports programme or with fundraising.

### *CE scheme*

The CE scheme is vital for the operation of the SIAA. The organisation rates the success of CE workers in obtaining direct employment as good, with 4 of 6 previous CE workers now in direct employment.

### *Training, monitoring and evaluation procedures*

The SIAA does not operate any accredited training programmes, but sees their potential value. The SIAA operates in-house induction and training programmes for its staff, CE workers and volunteers. The SIAA has written safety procedures in relation to its venture sports and other activities and adheres to these. The association has no stated complaints procedure (re employees), but has internal reporting mechanisms.

The SIAA has not, as yet, undertaken an independent organisational or service user evaluation. However, FAS carries out an annual organisational evaluation. The SIAA undertook an internal organisational evaluation in 1998. The association has used questionnaires to survey its membership about issues of concern and has developed campaigns for changes in existing regulations on the basis of the results. The association has a 5-year plan, with set targets in relation to the services it provides, staff numbers and premises.



## **PREMISES**

The SIAA is located in a 2-office prefabricated building in the grounds of the National Medical Rehabilitation Centre in Dun Laoghaire, Co. Dublin. This building is fully accessible. The SIAA is computerised and has drop-in facilities and uses of accessible meeting rooms. It has plans to move to custom-built offices in the foreseeable future.

## **SERVICES**

### **INFORMATION SERVICES**

#### *Resource centre*

The SIAA operates a resource centre at the National Rehabilitation Hospital. SIAA staff provide information on spinal injury, social welfare entitlements and grant assistance, housing and vehicle adaptations, use and availability of aids, appliances and equipment and employment.

#### *Publications*

The SIAA publishes a number of fact sheets and leaflets, which give general and specific information about spinal injury and its consequences. The SIAA has a quarterly newsletter, *Spinal News*, which provides families with information on developments in spinal injury and provides a forum for discussion and exchange. The association publishes an annual report

### **SUPPORT SERVICES**

#### *Support unit*

The SIAA runs a support unit staffed by two people with spinal injuries. Anyone with a spinal injury can contact these individuals who will provide support and advice.

#### *Family support network*

The SIAA has a support network which enables people in similar situations to get in contact with others. This assists people with spinal injuries, their partners and families.

#### *Outreach service*

The SIAA operates a national outreach service to anyone with a spinal injury. If a person with a spinal injury contacts the organisation, the support coordinator visits that person and finds out about their situation. A core aim of this service is to encourage people to become active members of their community again. The support coordinator encourages the individual to become involved and seeks employment training opportunities for them locally.

### **RECREATION SERVICES**

#### *Venture sports programme*

Following on the American experience which has shown that venture sports have a positive effect on the well-being and self-regard of people with a spinal injury, the SIAA has developed an outreach programme and has set up a *Wild seal's venture club*. This club enables people with spinal injury to enjoy canoeing, sailing and angling. The club organises multiple activity venture outings during the year.

The SIAA also runs weekly training in self-defence, in Dublin. This is the first martial arts' club for people with a disability and it incorporates a 6-week certification course. The SIAA also runs a scuba-diving club, the first of its kind in the country, affiliated to the Irish Underwater Council (CFT).

The SIAA considers that, beside the benefits of participation in sport, participants on this sports programme can begin to rebuild their self confidence and to relish the challenge involved. The SIAA considers that improved self-esteem enables people with spinal injury to re-evaluate their lives and to make choices about what they want for themselves.

#### **VOCATIONAL/TRAINING/EMPLOYMENT SERVICES**

About 80% of people with spinal injury are unemployed. The SIAA has undertaken a survey of its members on employment. Through the support coordinator, the SIAA seeks to assist people with spinal injury to access vocational and employment services.

#### **INDEPENDENCE SERVICES**

The SIAA acts as a non-benefiting broker in arranging PA services for its members who require personal assistance.

#### **ADVOCACY SERVICES**

The SIAA is the national representative body for people with spinal injuries. The SIAA considers that if people with a disability are to be better served, greater cooperation is needed between organisations providing services and support to people with disabilities. As such, it advocates and supports the establishment of common goals and a unified approach by all voluntary organisations working for people with disabilities.

The SIAA campaigns for improvements to services through its newsletter. The SIAA supports individuals in their efforts to obtain services through the health boards and other regional and national agencies. The SIAA conducts campaigns on behalf of its members.

#### *Links with other organisations*

The SIAA has direct contact with the Department of Health and Children and the Department of Equality and Law Reform. It has little direct contact with the health board administrative structures. The SIAA has ongoing involvement with Independent Living Community Services (ILCS), the Center for Independent Living (CIL), the Forum for People with Disabilities, the National Disability Authority (NDA) and Disability Federation of Ireland (DFI).

# VOLUNTEER STROKE SCHEME

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## INTRODUCING THE VOLUNTEER STROKE SCHEME

The Volunteer Stroke Scheme was founded in 1983 to provide support services for people with speech and other problems as a result of a stroke. In the past 10 years, the scheme has opened 4 new stroke clubs and has provided physiotherapy services free of charge. It has also set up and maintained its free, technical aid loan bank. The Volunteer Stroke Scheme provides information services, runs clubs, outings, holidays and relative support groups, arranges home visits by volunteers and supplies technical aids. It seeks to raise public awareness and understanding of the outcomes of strokes, through effective and relevant publicity.

In the past number of years, the Volunteer Stroke Scheme has found it increasingly difficult to recruit and retain volunteers. Its activities are inevitably limited by lack of core funding. It also points to its perception of public anger at the lack of community-based services for people with disabilities and, in particular, to the lack of a government commitment to stroke care and rehabilitation.

## MEMBERSHIP AND BOARD STRUCTURE

The Volunteer Stroke Scheme has a national membership. Services are provided to nonmembers. The Volunteer Stroke Scheme is a company limited by guarantee and has a charity number. The board of management comprises 6 people who meet 14 times a year.

## INCOME AND EXPENDITURE

The Volunteer Stroke Scheme has an income of approximately £46,000 per annum. It receives no EU funding. It obtains a grant of £17,000 through the Eastern Health Board. It obtains £4,000 through the respite care scheme, funded through national lottery allocations. It

### STROKE

Stroke is the general term used to describe brain injury caused by a sudden interruption of blood flow in the brain. It is more common in adults than in children and mainly affects people in middle to old age. The causes of strokes include hypertension or high blood pressure. Depending on where in the brain the stroke occurs, the individual will have a series of symptoms which may include speech difficulties, memory and attention problems, weakness or immobility of one side of the body, affecting the face arm and/or leg.

Recovery from a stroke is a slow process and is aided by ongoing encouragement and by therapies for speech and movement.

Some people recover from a stroke and resume their lives as before. For other people, they may find some problems with concentration and have slight difficulties in locomotion. A small number of people have significant long-term problems with communication and mobility.

raises an additional £25,000 through its own fundraising programme. This includes marathons, quiz nights, donations, Christmas cards and coffee mornings.

#### **STAFF**

The Volunteer Stroke Scheme has 2 part-time (20 hours each) staff, neither of whom is administrative. The organisation does not participate in the CE programme. It has approximately 70-80 volunteers. The main expenditure of the Volunteer Stroke Scheme relates to the volunteer activities.

#### *Training, monitoring and evaluation procedures*

All staff and volunteers participate in induction training, including an accredited lifting and handling programme. The Volunteer Stroke Scheme has in-house training for staff and volunteers. The organisation uses the safety protocols recommended in accredited training programmes and has written safety and internal reporting mechanisms. The Volunteer Stroke Scheme has never undertaken any review of its work.

#### **PREMISES**

The Volunteer Stroke Scheme operates from an office in the Brainwave (the Irish Epilepsy Association) building. It pays for use of buildings, typically used by social services, to run its clubs.

## **SERVICES**

#### **INFORMATION SERVICES**

The Volunteer Stroke Scheme provides information to relatives about strokes and about health and social welfare services. It runs an annual open day and organises evening public lectures on relevant topics. It seeks media coverage of its services at least once a year. It produces a newsletter but not an annual report.

#### **MEDICAL/NURSING/THERAPEUTIC SERVICES**

##### *Therapeutic*

Physiotherapy is provided in the club setting.

#### **SUPPORT SERVICES**

##### *Stroke clubs*

The Volunteer Stroke Scheme operates clubs where people who have had a stroke may go and participate in a range of social activities. The scheme obtains most of its referral from the medical profession.

### *Relatives' support groups*

The Volunteer Stroke Scheme also runs relatives' support groups to assist any close relatives of a person who has had a stroke to come to terms with the changes in their lives and to cope with day-to-day requirements.

### *Helpline*

The Volunteer Stroke Scheme operates a helpline 3 days a week.

### *Respite services*

The Volunteer Stroke Scheme organises respite breaks, mainly holidays

### *Visiting services*

The Volunteer Stroke Scheme organises volunteers to visit people who have had a stroke.

### *Financial support*

The Volunteer Stroke Scheme has a hardship fund and will provide sums to enable individuals to obtain physiotherapy and similar services, in certain circumstances.

### *Equipment purchase or loan*

The Volunteer Stroke Scheme lends equipment to people with a stroke when necessary.

## **RECREATION SERVICES**

The Volunteer Stroke Scheme organises regular social outings and an annual holiday. It also organises a darts competition between clubs.

## **ADVOCACY SERVICES**

The Volunteer Stroke Scheme leaves advocacy to organisations which were set up and are funded to undertake this work. It points to Disability Federation of Ireland (DFI) and CNEASTA (the Irish council for training, development and employment for persons with disabilities) as examples.

# OVERVIEW

## ABOUT THIS GUIDE

This guide gives a range of details about Irish non governmental (voluntary) organisations for people with physical or sensory disabilities or for people with mental health problems. These organisations provide an extensive range of services and activities for their client groups. Each of the 56 organisations described here is a member of Disability Federation of Ireland (DFI), the national umbrella organisation for non-governmental, voluntary, disability organisations. The guide does not include information about DFI member organisations whose primary remit is in the provision of learning disability services. This is the first time that DFI has presented such an extensive survey of a range of its constituent organisations. The data provide valuable insights and raise many questions about service policy, design and delivery.

The data for this guide were collected from July 1999 to March 2000. The process of data collection included a lengthy questionnaire, an optional meeting, opportunities to provide additional material, and to correct and modify draft text. The information presented here was accurate at the time of collation or publication. Inevitably, it will age rapidly.

The information in the guide is incomplete. Organisations differed in their capacity and/or preparedness to give information, particularly in financial areas, and in the detail of some of their services. In relation to figures for income and expenditure, many organisations had access only to 1998 audited figures at the time of interview and, where these were available, they were included to assist in providing an accurate overview of the financial sources and expenses. The gaps in the information base, along with its lack of specificity, lead to limited comparability in many instances. Nonetheless, the guide constitutes a significant step forward in the transparency and understanding of the sector as a whole. It is now possible to make general comments about these DFI member organisations.

## A PICTURE OF THE SECTOR

The physical and sensory disability organisations, along with mental health organisations in this country, comprise a relatively large number of small bodies, many with highly specialised services directed at specific groups. The organisations described in this guide seek to address these distinct client groups; people with physical or sensory disabilities and people with mental health problems. While the numbers in each client service category preclude direct comparison, it is true to say that the range of services on offer through any one client category bears striking similarity to the services of the other client categories.

This overview looks at some of the general organisational and sectoral findings deriving from the guide. The overview is divided into sections which examine the data under specific headings.

1. Profile of the organisations: date founded and rationale for establishment;
2. Organisational structures: national/regional, membership and legal structures;
3. Services provided by the organisations;
4. Organisations' regionalisation of their service delivery
5. Income and expenditure of the organisations;
6. Funding sources of the organisations;
7. Staffing: numbers of directly paid staff;
8. Organisations' participation in the FAS CE programme;
9. Volunteers in the organisations;
10. Organisations' monitoring and evaluation procedures;
11. Organisations' views of their main achievements in the past 10 years;
12. Organisations' main concerns for the future;
13. Final remarks.

## 1. PROFILE OF THE ORGANISATIONS

### 1.1. Date of foundation

Organisations were asked to give their founding date. All but 1 organisation provided this information. Table I gives the details. In total, 8 (14.5%) were formed prior to 1959. It is salutary to reflect on the size of the voluntary sector at that time, in comparison to the present. Another 11 (20.0%) were formed in the period 1960-1969. This was followed by a relative lack of growth of the sector, in that 1970-1979 saw the emergence of only 6 (10.9%) new organisations. The growth of the sector increased dramatically in the 1980s: 21 new groups (38.2%) were formed in that decade. Relatively, the '90s showed more moderate growth, with 9 (16.4%) organisations founded in the period. We may speculate on the socio-political climates that facilitate or militate against the establishment of voluntary disability organisations.

Almost 2 in 5 of the organisations were founded in the 1980s.

Table I: Decade of foundation of the organisations (N=55)

Decade of foundation	No. of organisations
pre -1959	8
1960-9	11
1970-9	6
1980-9	21
1990-9	9
<b>Total</b>	<b>55</b>

### 1.2. Rationale for establishment

A large number of organisations gave more than one aim or rationale for existence. The reasons given exhibited certain clusters; mainly around either services and support or advocacy and entitlement. This was somewhat, but not completely, related to the year of foundation, with most of the small number of groups whose sole purpose was that of

advocacy being relatively newer. As a general remark, longer-established organisations viewed themselves as having a significant, if not primary, function to provide services, or in the case of small organisations, to provide a support network. Equally, as a generalisation, more recently-formed organisations were more likely to identify independence, or civil rights issues as a core or key concern. Many organisations have developed new or modified perspectives on their role in the course of their existence. Occasionally, a stated primary goal of an organisation was not necessarily obvious in its description of its service structure or its activities.

## **2. ORGANISATIONAL STRUCTURES**

This section of the overview gives brief details of the size and structures of the organisations. As part of this analysis, the organisations were categorised as either national (N=44) or regional (N=12) in scope. Generally speaking, the oldest organisations, both national and regional, are larger than others. At least half of the older organisations come from a medical model of intervention and services. Others were set up to provide post-medical intervention and have subsequently become large support and vocational services.

### *2.1. National organisations*

In total, 44 of the organisations in this guide (78.6% of the total) are national organisations, i.e. with a brief that includes the whole of the Republic of Ireland at the least. A small number have a whole-island remit, while others have links with similar organisations in Northern Ireland, or wish to foster such links, or wish to expand their operations into Northern Ireland. Fully 39 of the 44 national organisations (88.6%) are membership-based, while 5 (11.4%) are nonmembership-based.

#### 2.1.1. National membership-based organisations with a branch structure

Of the 39 national membership-based organisations, 20 (51.3%) have a national branch structure. The numbers of branches vary considerably: the largest number of branches is 86, the smallest is 3. It is interesting to note that those organisations with the largest numbers of branches need not be particularly large organisations in financial terms. The number of branches in a given organisation reflects the number of active volunteers, rather than its income or expenditure. Table II shows the details.

#### 2.1.2. National membership-based organisations without a branch structure

In all, 19 national representative, membership-based organisations (48.7% of the national membership-based group) have no branches. Most of these are small, or very small, organisations. Their memberships are usually geographically scattered. Some of these organisations deal with medical conditions which radically affect lifestyle, or are life-threatening. In these instances, members may be unlikely to form branch networks.



**Table II: Numbers of branches of membership-based national organisations (N=39)**

<b>Nos. of branches</b>	<b>No. of organisations</b>
no branch structure	19
1-9	8
10-29	6
30-49	2
50-99	4
<b>Total</b>	<b>39</b>

### *2.1.3. National nonmembership-based organisations*

In total, 5 national organisations, (11.4%), are nonmembership-based organisations. They are almost all large and are among the older organisations within the sector. The reasons for the nonmembership-based structures may include:

- ▶ the historical reasons for establishing the service;
- ▶ some types of organisations such as workshops and schools are not typically membership-based organisations in this country; and,
- ▶ in some cases, the potential service users' problems or needs are such that their participation as group members is unlikely, e.g. people who are homeless.

### *2.2. Regional organisations, membership-based and nonmembership-based*

For this analysis, 12 organisations (21.4% of all entries) were designated as regional, i.e. their remit extends within a single geographical area of the Republic of Ireland. Of these regional organisations, 3 have a membership base (25%) and 9 (75%) are nonmembership-based groups. From these figures, it seems that DFI national organisations are more likely to have membership-based structures than are its regional affiliates.

### *2.3. Number of members of membership-based organisations*

In total, 42 national and regional organisations (39 national and 3 regional) have formal memberships, while 14 are nonmembership-based in structure. Of the 42 with memberships, only some gave membership figures and others provided estimates of their membership on the basis of ongoing contact, of names on a mailing list and numbers who have paid a membership fee. This reflects a common problem for many organisations in collecting even small membership fees from individuals who feel themselves to be entitled to both the services and ongoing contact of the organisation. In all, 5 organisations stated that their memberships are family memberships. Organisations with fewer than 100 members are typically regional membership-based organisations. Most of the national organisations which gave figures have memberships between 300-2,500, with 9 organisations in this group having memberships between 300-500.

### *2.4. Legal structures*

Each of the organisations has some form of board of management or directors, which meets regularly, with varying frequency. Some of the smaller organisations find that rotation of board members is a difficulty, in that few members are available or willing to serve on

committees, with the result that the same people are often on a board for an extended period. Generally, boards do not apply upper or lower age limits. Some organisations expressed the wish to delineate a lower age limit in an attempt to include younger board members.

### 3. SERVICES PROVIDED BY THE ORGANISATIONS

In this section, the amalgamated data on service provision are examined. For the purposes of compiling the guide, services were examined under 9 broad service divisions. All services provided by the organisation were categorised under one of these headings.

**INFORMATION SERVICES** including websites, personal information and advice, public awareness and research

**EDUCATION SERVICES** including schools and other educational programmes which do not have a primary vocational purpose

**MEDICAL/NURSING/THERAPEUTIC SERVICES** provided by trained personnel

**SUPPORT SERVICES** including home-based assistance, professional and other counselling services, respite services, financial assistance and equipment loans

**RECREATION SERVICES** including ongoing and annual activities

**VOCATIONAL, TRAINING AND EMPLOYMENT SERVICES**

**HOUSING SERVICES** and other accommodation services

**INDEPENDENCE SERVICES** including personal assistant (PA) services

**ADVOCACY SERVICES** including national advocacy, advocacy on behalf of individuals and the fostering of self-advocacy skills. Within this guide, other synonymous terms include representation and lobbying.

#### 3.1. Numbers of services undertaken by organisations

The numbers of services provided by organisations were counted. The results are presented in Table III. Most organisations provide between 4 and 5 different services. Relatively few provide 2 or less or provide 8 or more.

**Table III: Number of services provided by organisations (N=56)**

No. of services	No. of organisations
1-2	6
3	5
4	12
5	14
6	7
7	7
8	3
9	2
<b>Total</b>	<b>56</b>

### 3.2. Types of services most commonly provided by individual organisations

The types of services provided by each of the organisations were counted. The results are presented in Table IV. The most commonly provided services are information, support and advocacy services. In total, 52 organisations (92.8%) provide an information service and 50 (89.3%) provide a support service of some kind while 47 organisations (83.9%) provide an advocacy service. Housing and education services are the least commonly provided. Some services, e.g. medical/nursing/therapeutic or education, are not relevant to certain groups of service users and this may partially explain the low numbers of organisations involved in their provision. An additional issue may be the cost of these services - only large and well-funded organisations are in the position to employ professional medical, nursing, therapy or teaching staffs.

**Table IV: Numbers of organisations providing specific services (N=56)**

Service	No. of organisations providing*
Information	52
Education	14
Medical/nursing/therapeutic	23
Support	50
Recreation	31
Vocational/training/ employment	24
Housing	11
Independence	19
Advocacy	47

\*Organisations typically provide more than one listed service

### 3.3. Lack of direct comparability of services

It is important to note, that the scope of services provided by the organisations may not be directly comparable. For example, some organisations may operate full-scale primary and secondary education services, while others may run a literacy course as an education service. Differences in the scope of services are also evident in the range and frequency of support services offered by different organisations. As a general statement, small organisations provide fewer formal or ongoing services than their larger counterparts. This lack of direct intrasectoral service equivalence precluded a comparative analysis of the range of services on an offer under any discrete service heading.

#### **4. ORGANISATIONS' REGIONALISATION OF THEIR SERVICE DELIVERY**

Within and outside the sector there is considerable interest in examining the issue of regionalisation of national services. This section seeks to provide some preliminary findings in this regard. The data give only a partial picture of the extent of regionalisation of services because some organisations did not provide details of the location of their services. In addition, some organisations may have had a short-term service in one or more health board regions, often associated with EU funding which is now almost at an end, and which will not be continued with other funding.

The purpose of a national organisation is relevant when discussing regionalisation. Some types of services lend themselves to a single location: general information services and national advocacy services being good examples. Some organisations have an extensive publications reservoir, coupled with supportive telephone contact systems which together provide many, but not all, of the benefits of a localised face-to-face information service. Equally, a national advocacy organisation may find regionalised services (but not necessarily regional branch structures) to be unnecessary. On examination, up to 7 national organisations provide a service which appears not to require a regional service infrastructure. Examples include organisations which are umbrella groups of some kind, or typically provide an information/research/advocacy service, or provide a residential service. Thus, the discussion about regionalisation of services relates, at a minimum, to 37 national organisations, all of which provide one or more staffed contact services, in at least one health board region.

Only 1 in 4 of the national organisations provides one or more staffed services in each health board region. Many organisations provide services in only one or a limited number (max 6) of the health board regions. Some of the national service organisations have no regional delivery of services.

##### *4.1. What constitutes a regional service?*

All of the national organisations with an extensive branch structure have a resulting regional presence. Many of these branches arrange meetings or provide an informal support network. This is quite different from the provision of staffed services. In this section, remarks are confined to formal regional service provision as opposed to regional branch presence.

The analysis examined organisations in a number of different categories:

- ▶ national organisations with staffed services in each health board region;
- ▶ national organisations with staffed services confined to a limited number of the health board regions; and
- ▶ national organisations with formal services located in only one health board region.

Despite the limitations of the material and the generalisations which inevitably hide real differences between services, it is possible to make a number of broad statements about the nature and extent of regionalisation for the 37 national organisations for whom regionalisation is a legitimate service goal.

#### *4.2. National organisations with staffed services in each health board region*

In total, 9 of the national organisations under discussion (24.3% of the 37) have some form of staffed service in all health board regions. For some of this group, this means specified locations for services, including dedicated premises. For others, it means an active county or regional branch which fundraises and subsequently sources and funds a limited local range/availability of professional services. For virtually all of those organisations providing services in every health board, the range and scope of the services provided in the Dublin area are considerably greater than that in any other area of the country. These data raise questions about equitable service delivery and about the extent of true regionalisation of these services for these client groups.

##### 4.2.1. Services in each health board by outreach

In total, 3 organisations (8.1% of the 37) have services primarily directed from a single location (usually Dublin) but provide an outreach service from the headquarters to any part of the country. Sometimes, in addition, these organisations source local professional services, either nursing, care or counselling. Some organisations, particularly those seeking to assist people with terminal medical conditions, have an individual or a small team on permanent standby to provide an outreach response to crisis, often to serious illness or imminent death. Frequently, the call on the service reflects a family's wish that a person will die at home. Some organisations respond to information requests through a mobile unit. Others have a national equipment loan system.

#### *4.3. National organisations with staffed services confined to a limited number of the health board regions*

In total, 9 of the 37 national organisations (24.3% ), with a legitimate aim of regional service provision, provide services in 2-6 of the health board regions. Of these, 2 organisations provide services in only 2 health boards, 3 organisations provide services in 3 health boards and 3 have a service structure of some kind in 5 health boards and 1 has a variable range of services

Those organisations with any regional development of services typically have only a limited number of their full range of services on offer in any region outside Dublin and/or have regional services in only some of the health boards. Most organisations are aware of the inherent inequity of this situation but see little remedy.

in 6 health boards. This means that, for members of these organisations and/or their service users, their domicile in a given health board region gives or precludes potential access to services. Many of the organisations in this position commented on the obvious unfairness of the situation and their sense of powerlessness to rectify this inequity.

#### *4.4. National organisations with staffed services in only one health board region*

In total, 14 of the 37 relevant national organisations (37.8%) have no regional delivery of services and no formal service base or structure outside of Dublin or some other single central headquarters. All of these organisations provide an information and advocacy service from their central (usually Dublin) office. This group includes 5 national organisations which seek to provide national services and which currently operate from one centre only (usually Dublin) and have no branch, outreach or sourced services. They wish to regionalise their services and some have detailed plans in this regard. This group also includes 5 organisations which have a Dublin-based service with support branches in most, but not all health board regions.

#### *4.5. Dublin as a hub*

Some of the organisations have come up with novel approaches to the difficulty of regionalising their services. A striking feature of the operation of many of the small to medium organisations is the use of Dublin as a hub. Some have confined their operation to the single centre (usually Dublin) and have used freephone numbers, the postal system and computerised communication to respond to information queries and to provide support to individuals.

##### 4.5.1. Inflow to Dublin

Some organisations provide direct interface services for people living in or around Dublin, or for people who can travel to Dublin only. For some groups, the necessity to travel to Dublin to attend medical appointments at national hospital centres provides the organisation with a possible way of making contact. Recognition and acceptance of a voluntary organisation representative at these medical clinics are growing phenomena. As part of this trend, 11 national organisations (25.0%) whose client groups require highly specialised medical services either have, or are actively campaigning for, a single, national medical centre located in Dublin or a specialist nurse (liaison nurse) service.

## **5. INCOME AND EXPENDITURE OF THE ORGANISATIONS**

This section looks at the financial size of the organisations. All were asked to give details of their income and expenditure for a given year. Many organisations did not give complete data, often confining the figures to some or all aspects of expenditure and not delineating their sources of income. As a result, the sectoral data on income and expenditure are fragmentary.

Some organisations provided audited accounts. These were less informative than might have been expected, due to auditing practices. Many, but not all, auditors amass all or most income through grant sources into a single figure and do not provide a breakdown of the sources of these grants. This practice precluded the examination of the sources of central and regional State funding, where relevant.

It is possible to collate some general financial information for those organisations which provided figures. The best documented figures relate to total expenditure. It should be noted that many organisations specifically excluded the contribution made to the organisation by FAS (the national training and employment authority) through Community Employment (CE). In the case of some organisations, it is not clear whether the CE funding component is included in overall expenditure figures.

### *5.1. Approximate expenditure figures: national organisations*

Of the 44 national organisations, 36 (81.8%) gave approximate expenditure figures or these could be found by addition. A total of 2 national organisations did not produce annual figures as they receive no income other than occasional grants to assist in conferences etc. All figures were rounded to the nearest thousand for this analysis and CE sums were excluded, if known.

In all, 20 of the 36 national organisations (55.5%) have a budget of less than £300,000, with 12 of these having a budget of between £100,000 and £299,000. A total of 9 organisations (25.0%) can call on annual resources of between £300,000 and £900,000. While 7 organisations (19.4%) have a budget of £1m or more, it is apparent that there are sharp differences in the size and scope of these groups. The results are presented in Table V.

**Table V: Approximate annual expenditure of national organisations (N=36)**

Expenditure (approx.)	No. of organisations
£74m	1
£4-7m	3
£1-3m	3
£600,000 - £999,000	4
£300,000 -£590,000	5
£100,000 -£290,000	12
£50,000- £90,000	2
£10,000- £49,000	6
<b>Total</b>	<b>36</b>

*5.2. Approximate expenditure figures: regional organisations*

In all, 8 (66.6%) of the regional organisations gave details of their annual figures. These show a dispersed financial pattern. Fully 37.5% of those giving figures have less than £20,000 per annum to spend, yet 50% have budgets of more than £300,000. See Table VI for details.

**Table VI: Approximate annual expenditure of regional organisations (N=8)**

Expenditure (approx.)	No. of organisations
£4-7m	1
£1-4m	0
£600,000 - £999,000	1
£300,000 -£590,000	2
£100,000 -£290,000	1
£21,000 -£99,000	0
less than £20,000	3
<b>Total</b>	<b>8</b>

## 6. FUNDING SOURCES OF THE ORGANISATIONS

This section of the overview looks at the available information on the sources of income for the sector. The main funding sources for organisations include:

- ▶ European Union (EU) funding, usually through the Horizon programme;
- ▶ central Irish State funding, usually FAS (the national training and employment authority), through its Community Employment (CE) programme, the Department of Health and Children and, less frequently, the Department of Education and Science or the Department of Social, Community and Family Affairs. Other State funders of the sector include the National Social Service Board (NSSB), the Health Promotion Unit (HPU) and the National Rehabilitation Board (NRB);
- ▶ regional State funding, i.e. the health boards;
- ▶ trust funds -People in Need is mentioned most frequently;
- ▶ charitable fundraising through flag days, annual events and through commercial activities small businesses and charity shops.

The analysis in this section is attenuated by the incomplete and non-comprehensive information available. Not all organisations listed their sources of income. Some listed only their charitable sources and did not give the sources or amounts of statutory funding. In particular, EU, central and regional State funding agencies may fund organisations in this guide which have not acknowledged these funds. Any remark made in this section about the extent of funding from a given source must be taken as an indicator of its minimum financial support of the sector.

### *6.1. European Union funding for organisations*

At least 13 organisations (23.1%) have been funded by one or more EU programmes.

European Union funding sources come in the main through the Horizon programme. This funding programme has been a positive contribution for both national and regional organisations and has been an enabling source to test or establish regionalisation, albeit on a highly limited scale. Other EU programmes for arts or education or the Peace and Reconciliation funds are occasionally mentioned.

### *6.2. Central State funding for organisations*

#### 6.2.1. FAS

Central State funding comes in the main from FAS which is the national training and employment authority. At least 53.6% of all organisations participate in work schemes funded through the Community Employment (CE) programme and 21.4% are reliant upon one or more of these schemes for their continued existence and/or operation. In a minimum of 4 instances (7.1%), the organisation's CE participation was valued at a sum greater than all other expenditure. Many of the organisations discounted the FAS CE funding, possibly because they have little control over the spending of it. Nonetheless, it is a significant source of ongoing and substantial funds for both national and regional groups. The organisations' views on the operation of the CE schemes are discussed in some detail in section 8 of this overview.



### 6.2.2. Department of Health and Children

In all, at least 17.8% of all organisations specifically named the Department of Health and Children as an ongoing, or occasional or once-off funding source. This department has been a core funder of some national organisations and hospitals. The statutory funding conduits for these organisations were in the process of change at the time of the completion of this study. Some organisations obtain funds from the Department of Health and Children, through its discretionary national lottery fund. In these cases, the grant was often, but not always, a once-off response to the organisation.

### 6.2.3. Other government departments

Funding from the Department of Education and Science goes to groups with educational establishments. Some organisations criticised the Department of Education and Science's lack of preparedness to fund more general education programmes. A small number of groups obtain funds through the Department of Social, Community and Family Affairs.

### *6.3. Regional State funding (health boards)*

Issues in relation to health board funding are well-rehearsed within the sector generally. The data deriving from the present research provides limited scope for analysis. This is because not all of the national organisations gave details about the extent of funding from each of the health boards. As already noted, auditing practices used within the sector generally do not give detailed analyses of grant sources.

#### 6.3.1. No regional health board funding for many national organisations

A striking feature of the regional funding of the national organisations which gave detailed regional income figures is its paucity. Some national organisations receive no regional health board funds. Some organisations which provide services in more than one health board region identified the only health board source as the Eastern Health Board, a traditional funding mechanism for small, Dublin-based national organisations.

#### 6.3.2. Low levels of regional health board funding for national organisations

Another characteristic of the health board funding profile is the exceptionally low level of grant-aid received by national and regional organisations from the health boards. For example, sums of £1,000 from individual health boards, sometimes equal to no more than 0.2% of an organisation's national annual expenditure, appear derisory. The sporadic dispersal of health board funding also creates problems in trying to provide a coherent overview. In some instances, a given health board may have provided funds in one year only and have stipulated that no further funding would be given. Some groups gave instances of health boards providing funds over a period of years and then decreasing or stopping the funding for no apparent reason.

#### 6.3.3. Some regional health boards give more than others

Some of the regional health boards are named more frequently than others as a grant agency (albeit for small sums). During the collation of this guide, the national organisations repeatedly remarked on the injustice, inadequacy and absence of transparency of health board funding. They also pointed to specific health boards as particularly poor funders or being particularly unprepared to enter into dialogue about potential funding. The figures in this guide support these criticisms.

#### 6.3.4. Contrast with regional health board funding of regional organisations

In contrast, most, if not all of the regional organisations obtain some form of funding from the local health board. On the basis of the figures presented in this guide, it may be that at least some of the regional health boards are more prepared to fund regional organisations than regional services of national organisations. The evidence presented here suggests that, at the very minimum, some regional health boards may give higher proportional funding to regional organisations than to regional services of national organisations.

From the details obtained in this compilation, it is impossible to observe exactly what individual regional health boards believe is their legitimate responsibility in terms of funding regional services provided by national organisations. Equally, it is unclear as to what any given regional health board could expect to obtain in terms of services through such small sums. At least superficially, many of the health boards appear to behave as if they were charitable benefactors, rather than State-funded agencies with a remit to ensure regional service delivery.

#### *6.4. Organisations' reliance on State funding*

As a general remark, the larger the organisation the greater the reliance on State funds, although there are notable exceptions. Some smaller organisations have to fundraise up to 70 - 90% of their income through charitable donation sources. It is unclear why one group should be relatively well-funded by the State and another similar group should receive less than 10% of their income through State sources. A small number of organisations receive no State funding, central or regional. Some of these are recently formed, or are very small.

#### *6.5. Occasional additional funding sources for regional organisations*

Occasional additional funders of the regional organisations include the area-based partnership of the local area and the Combat Poverty Agency.

#### *6.6. Fundraising income*

Almost all organisations seek charitable donations and fundraise through a variety of traditional and some innovative means. A small number of organisations do not seek any charitable funding. Most of these are either precluded from doing so, or are fully funded through the EU and/or the exchequer. One organisation is opposed to fundraising on principle, believing that core services should be provided to people with disabilities as of right not as a charity. Some other organisations expressed this view, but continue to seek charitable donations. Some of the larger organisations run national charity projects, sell equipment or specialised services to obtain funds.

##### 6.6.1. Ability to fundraise

Some organisations find it easier to fundraise than others. Older, well-established groups would seem to be at an advantage over newcomers. Some larger organisations commented on the increasing difficulty in getting the public to donate, in part due to the effects of the operation of the National Lottery. Organisations with a highly developed branch structure are more likely to obtain funds from the general public. Conversely, little-known organisations with no branch structure find fundraising onerous. For regional organisations, fundraising may be relatively easier, possibly because they are more likely to be known to their neighbours. A number of organisations commented on the stigma attached to the medical condition (physical or mental) of their membership as a significant factor in low fundraising returns.

### 6.6.2. The cost of fundraising

Some organisations commented on the cost of fundraising. A number of them gave figures indicating that between 40p and 55p of every £1 gross of fundraising income went on the expenses associated with its procurement. A number of organisations have recently developed a fundraising programme and had found the set up costs to be significant and are unsure that their operations will become profitable in the near future.

### 6.6.3. Extent of dependence on fundraising

Some organisations described themselves as dependent on charitable fundraising. In some instances, it is possible to see exactly the percentage of income deriving from fundraising, and therefore the exact level of reliance. Some organisations are entirely dependent on fundraising/trust or other voluntary agency donation (N=3, 5.4%). Other organisations have a high reliance on fundraising. Some organisations gave details of fundraising 25% of a multimillion pound budget. Others fundraise 70 -84% of budgets ranging between £300,000 - £900,000. Other percentages include organisations fundraising between 18 -50% of income. For yet other organisations, their stated reliance is presented without detailed figures. It is, therefore, impossible to state how reliant they are on these funds.

### *6.7. National voluntary organisations' funding of acute and other hospital services*

A number of the national voluntary organisations use their own funds to pay for services within the Irish health system. This includes funding of core equipment for acute and other hospitals, and funding or part-funding of staff in hospitals. Another puzzling funding loop is observed when the Department of Health and Children provides funds to a voluntary organisation to fund core services for the organisation's service users in a national hospital centre. These findings raise questions about the State health policy that allows or, perhaps, encourages these practices.

## **7. STAFFING OF THE ORGANISATIONS**

This section looks at staffing issues for the organisations included in this guide. Staff may be directly paid by the organisation, may be paid through one of the FAS-funded CE schemes or may be funded in part by a European Union (EU) programme. In the present study, most organisations made a distinction between directly paid staff and CE workers, but few made any distinction between directly paid and EU part-funded posts. It is possible that a small number of organisations included CE workers as core staff. These provisos must be kept in mind when examining the numbers presented in this section.

### *7.1. Numbers of directly paid staff*

#### 7.1.1. National organisations

The exact numbers of directly paid staff were estimated from the figures given by 42 of the national organisations; 2 national organisations did not give details of the numbers of staff employed. The results are presented in Table VII. In total, 25 (59.5%) of these national organisations have a staff level of 5 or fewer, with 7 (16.6%) having no directly paid staff. Some of these groups may have an entirely volunteer organisation, while some may be reliant on CE workers for all staffing. Less than 10% of national organisations have a directly paid staff of more than 100.

**Table VII: Numbers of directly paid staff in national organisations (N=42)**

No. of directly paid staff	No. of organisations
0	7
1-2	8
3-5	10
6-10	4
11-20	4
21-50	3
51-100	2
101 -300	2
301- 999	1
more than 1,000	1
<b>Total</b>	<b>42</b>

#### 7.1.2. Regional organisations

Relatively more regional than national organisations operate without a core staff. A total of 4 regional organisations (33%) gave details of having no directly paid staff. Exactly half had a staff of between 11-30, indicating a significant organisational structure. See Table VII for details.

**Table VIII: Number of directly paid staff in regional organisations (N=12)**

No. of directly paid staff	No. of organisations
0	4
1-2	1
3-10	0
11-30	6
31-100	0
more than 100	1
<b>Total</b>	<b>12</b>

## **8. ORGANISATIONS' PARTICIPATION IN THE FAS CE PROGRAMME**

This section examines some of the issues, comments and concerns raised in the course of this project in relation to the FAS CE programme and the CE schemes operated by individual national and regional organisations. In total, 22 national (50% of the national group) and 8 regional organisations (66.8% of the regional group), a total of 53.6% of all organisations, participate in one or more CE schemes. In all, 8 national organisations and 4 regional organisations are reliant for their continuing existence on CE workers (18.2% of national organisations, 33.3% of regional organisations, 21.4% of all organisations). Many organisations use CE schemes to provide staff for certain core services. In particular, some organisations are highly reliant on CE workers to deliver PA and other personal assistance or care services.

### *8.1. National organisations participating in CE schemes*

A total of 22 of the 44 national organisations (50.0%) stated that they have direct participation in a CE scheme. Of these, 18 gave the numbers of workers on the scheme in operation. Clearly, these figures may fluctuate and may no longer be applicable. At the time of the survey the largest number of CE workers with any organisation, which gave figures, was 466, while the second largest number was 180 workers. In all, 6 organisations gave details of having 1-2 CE workers and 6 have 4-8 CE workers while 4 organisations have between 23-60 CE workers.

### *8.2. Regional organisations participating in CE schemes*

Similar to the national organisations, regional groups have extensive involvement in CE schemes. In total, 8 (66.6%) participate in a CE scheme, with some groups almost entirely reliant on the scheme.

### *8.3. Criticisms of CE by organisations participating in the schemes*

Most organisations participating in CE schemes expressed general satisfaction with their involvement in the programme. Many of these organisations have a long history of involvement with CE. A number of the participating organisations complained about certain features of the operation of the schemes. Criticisms of the selection procedures, the FAS training given prior to and during the placement of workers, the work schedule (which was considered to be disruptive) and the constant turnover of staff were noted. A small number of participating organisations complained about the administration of the schemes, including problems getting payment from FAS. Most, but not all of the organisations which are reliant on FAS for their continued existence, commented that they valued the funding but found it lacked a developmental potential for the organisation and, in that sense, CE was limited and limiting in its real value.

### *8.4. Placement of CE workers in subsequent mainstream employment*

The organisations were asked to give figures on the number of CE workers who went on to gain mainstream employment. Mainstream placement rates varied between 20% and 100%. Dublin placement rates were generally higher than for other areas. Low placement rates were more common in rural areas and along some areas of the western sea board. Rates of placement into mainstream employment following CE were generally lower for regional organisations than for national organisations. However, the organisation with the single highest rate of placement was a regional organisation.

### *8.5. National organisations not participating in CE schemes*

Fully 23 national organisations (52.3%) gave no information on participation in any CE scheme. A total of 5 of these organisations (21.7% of the 23) stated that their nonparticipation was because of extreme dissatisfaction with the operation of the schemes or because of principled stances in relation to the rights of privacy and confidentiality of service users or in relation to objections to the CE workers' low pay rates.

## **9. VOLUNTEERS IN THE ORGANISATIONS**

This section looks at some of the information about volunteers in the organisations. A total of 33 of the 56 organisations (58.9%) gave details of volunteers.

### *9.1. National organisations*

In all, 27 national organisations (61.4%) have volunteers. At one end of the scale, some organisations are virtually entirely dependent on volunteers for services or for fundraising (N=4, 9.1%). At the other end are organisations which can call on 10-20 volunteers for flag days or other once-off funding events (N=7, 16.0%). Between these extremes are organisations which have the ongoing services of up to 100-300 volunteers who provide unpaid support services or are otherwise active at a local level.

### *9.2. Regional organisations*

Exactly half of the regional organisations have volunteers. For most of these organisations the volunteers provide unpaid visiting or other support services or act as unpaid drivers.

### *9.3. Volunteer policies*

Organisations were asked to note whether they have volunteer recruitment and retention policies, induction programmes, safety procedures and whether they use internal or external training opportunities. The numbers of organisations providing any of these features are presented in Table IX. Given that the organisations with safety policies also indicated a range of approaches within that policy, the numbers presented here indicate that most organisations have none of the volunteer training and monitoring mechanisms discussed.

For the 27 national organisations with volunteers, 6 have a volunteer policy and 2 are preparing a policy (29.6% of the 27). These organisations typically have relatively large numbers of volunteers who have physical contact with service users. Some organisations use volunteers only for fundraising activities. In these instances, the procedures relating to induction and training may be less onerous than for organisations using the services of volunteers to provide direct, physical contact services.

**Table IX: Types of formal approaches to volunteer involvement**

Type of volunteer approach	No. of organisations indicating use*
Volunteer policy	6
Recruitment and retention strategies	5
Induction programme	8
Safety procedures	7
External training	3
Internal training	8

\* organisations could note more than one approach

## **10. ORGANISATIONS' MONITORING AND EVALUATION PROCEDURES**

In the course of the survey, organisations were asked about ways in which they ensure their staff's performance and evaluate their organisational effectiveness. The findings show a limited number of organisations with a systematised approach to staff activities and wider organisational concerns. In some instances, this probably reflects the small size of the organisation or the high level of trust between staff and service users. In others, it may reflect lack of funds to formulate and implement these procedures.

### *10.1. Staff training and performance monitoring procedures*

The survey sought information about staff induction, training and monitoring procedures. Less than half of the organisations gave details about any of these issues. Of those organisations which responded, the most common procedure is some form of internal reporting mechanism. This was cited by 23 (41.1%) of all organisations. Fully 20 (35.7%) have a defined induction system and 17 (30.4%) have written safety/complaints procedures. Smaller numbers indicated that they have accredited or other training programmes, in-house or external. For some organisations the issue of monitoring procedures distilled to physical and sexual safety. In other instances, the concept of monitoring was a wider one, embracing all aspects of a quality service delivery. The data are summarised in Table X.

**Table X: Types of staff training and monitoring procedures**

<b>Types of organisational procedures</b>	<b>No. of organisations*</b>
Formal internal reporting mechanisms	23
Induction training	20
Written safety/complaints procedures	17
In-house training	14
Accredited external training	7
Accredited in-house training	6
Other external training	4

\* organisations could note more than one approach

### *10.2. Organisational evaluation or review procedures*

A second aspect of organisations' monitoring related to evaluations or reviews of services or of the organisational structures or mechanisms. In this context, an evaluation is an extensive examination of operations with definite proposals for change, while a review may be less systematic or have less obvious implication for the future. Either process may be internal (ongoing or occasional) and/or external and independent. Either may focus on service users or on management issues or both. A total of 12 of the 56 organisations (21.4%) had undertaken an independent evaluation/review of some aspect of their functioning. In total, 19 organisations have had a formal internal review, 9 of which have also had external evaluations/reviews. Thus, 34 (60.7%) of the organisations surveyed gave no details of any formal internal or external revaluation or review of any aspect of their operations. These findings are presented in summary in Table XI.

**Table XI: Organisational evaluation/review procedures of the organisations (N=56)**

<b>Procedure noted</b>	<b>No. of organisations</b>
No formal internal or external review	34
Internal review only	10
External review only	3
Internal and external reviews	9
<b>Total</b>	<b>56</b>

## **11. ORGANISATIONS' VIEWS OF THEIR MAIN ACHIEVEMENTS IN THE PAST 10 YEARS**

All organisations were asked to give a self-generated list of major developments in the past 10 years of their existence. Just over half of the organisations offered their view(s). It must be noted that for some recently formed organisations the question was not relevant. Many of the organisations which did not itemise a specific development commented that their continued



existence during the past 10 years was an achievement in its own right. A small number of organisations listed developments on all fronts.

For the 30 (53.6%) organisations which itemised a central achievement, 21 (70.0% of respondents) named specific service or organisational developments, 6 (20.0% of respondents) noted successful campaigns for changes in government policy or political approach and 3 (10.0% of respondents) itemised research/publications developments through their own activities or funding. These data are presented in Table XII. This pattern was in general keeping with the stated aims of organisations as described above in section 3 of this overview. It suggests that most organisations have a sense of success, even if, in conversation, this is attenuated by a general sense of the enormity of their task.

**Table XII: Organisations' perceptions of their main achievement (N=30)**

Main achievement	No. of organisations
Service development	21
Campaign success	6
Research/publications	3
<b>Total</b>	<b>30</b>

## 12. ORGANISATIONS' MAIN CONCERNS FOR THE FUTURE

Organisations were asked to itemise the 5 main issues that confront them now. The survey format did not provide a template. The lists were self-generated by the organisations. A total of 31 organisations (55.4%) gave a definite response. In all, 20 (64.5% of respondents) identified funding as their major concern. In total, 4 organisations (13.0%) commented that their main problem was the development of public awareness or acceptance of the condition. Another 4 (13.0%) commented on problems of recruitment, of members, volunteers, CE workers or staff as their overriding concern. Only 3 (9.7%) organisations identified the absence of services provided by and through the State as their principal concern, although some organisations included it in a longer list. Other priority problems raised by a significant number of groups in their lists of concerns included staff recruitment and retention in the context of rising pay rates and inadequate core organisational funding in the context of satisfactory levels of ongoing project-based income sources.

In all, 64.5% identified funding as their major concern while 13.0% of organisation considered that their main problem was the development of a public awareness or acceptance of the condition. Another 13.0% cited problems of recruitment, of members, volunteers, CE workers or staff as their overriding concern.

## 13. FINAL REMARKS

This guide presents a first sketch of how organisations differ in size, in the range of services they provide, in the sources of their income and their reliance on fundraising. It gives an initial glimpse of serious issues confronting the sector including funding, reliance on CE, and the

formulation and implementation of safety, reporting and evaluation procedures. The range of approaches and activities described here may assist organisations to continue to develop their own responses to existing and potential service users. This overview presents some of the most striking features and commonalities of the information in this guide. Despite the many difficulties that individual organisations face, it is apparent that the sector is alive, has a sense of its own mission and impact, that it seeks to respond positively at national, regional and local levels and is keen to improve its own transparency as part of an implicit or explicit contract to open a wider debate for and about the sector.

**Disability Federation of Ireland (DFI)** is the national umbrella organisation for the disability voluntary sector. This guide gives extensive details of 56 DFI member organisations providing services at both national and regional levels to people with physical or sensory disabilities or with mental health problems. These services range from information, advice and advocacy, through to education, medical and support services, to vocational, employment, housing and independence services. The guide includes an overview which presents, for the first time, some generalisations about the activities and outlook of these organisations. It is an essential handbook for voluntary organisation staff and for government, health board and other public service officials.

Price: IR£20.00

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