A Survey for the

Post Polio Support Group

Polio

The Late Effects Reality

PPSG

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"People with disabilities do not want to be pitied, nor do they want their disabilities to be dismissed as of little importance. All that is required is a little respect and basic needs and rights. Surely that is not too much to ask?"

Submission to The Commission on the Status of People with Disabilities
(Strategy for Equality, 1996)

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FOREWORD

The Post Polio Support Group celebrated its 10th birthday in 2003. So, it seemed appropriate, when we were planning the celebrations the previous year, to commission a survey to see both what had happened over the past decade as well looking at our members' specific needs past, present and future.

We did not realise at the time the enormity of the task we were undertaking. In reply to our invitation to participate in the survey we had a final take up rate of over 50%, which, in anybody's language, is magnificent, especially when the detail of information is realised. Some of it was extremely intimate and detailed.

The only criteria that we had were that the respondents had to be within the Republic of Ireland and to have had paralytic Polio at some time during their lives. Age, sex, occupation had no bearing as Polio struck at all members of the community. In the "good old days" it was a disease which marked an emerging and changing society where the "public infra hygiene structure" in Ireland was nowhere as developed as today.

I wish to thank all those who took part, the participants and those who worked on the project, for the way they gave their time so generously. Also, I wish to thank the Occupational Therapists who undertook the interviews, often going far beyond the call of duty to give help and advice to our members. Finally, I want to acknowledge John McFarlane, the author, for his towering work in compiling and writing this report.

I hope that the recommendations that come from this report will help not just our members, but all those who know of someone who had Polio in the past. There are also lessons here which we as a nation have a moral responsibility to make known on the international stage and in so doing assist the world-wide population of people with Polio and the **Late Effects of Polio.**

Jim Costello PPSG Chairperson, September 2003

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AIMS & OBJECTIVES

Aims:

1. To research the history of post paralytic Polio amongst the members of the Post Polio Support Group (PPSG).
2. To identify the effects, problems and ongoing needs that result from the Late Effects of Polio (LEP) amongst the membership of the Group.
3. To investigate the sociological results of LEP.
4. To quantify the cost of daily living requirements both amongst the membership and in the total Post Paralytic Polio population within the Republic of Ireland.
5. To secure funding and commitment from Government to support the needs of those with LEP.

Objectives:

1. The identification from within the Membership of the Post Polio Support Group (PPSG) of those who are medically diagnosed as experiencing the Late Effects of Polio (LEP).
2. An investigation to identify how LEP effects their daily lives in social, economic, personal and domestic terms.
3. A review of the life experiences of those with LEP through both a questionnaire and an iterative medium (interviews).
4. The identification of the effects of paralytic Polio in the education of respondents and its long-term consequences.
5. The identification of the carer's role in the lives of those with LEP.
6. The quantification of daily living needs of those with LEP, both in equipment and monetary terms.
7. The identification of the potential population of those affected by LEP within the Republic of Ireland based on an international research critique.

EXECUTIVE SUMMARY

The existence of the Late Effects of Polio (LEP) [also sometimes referred to as Post Polio Syndrome (PPS)] is recognised as a medical fact (Ahlstrom et al, 1993, Falconer, 1999, Hardiman, 1999). However, it is only now that the true consequences in human terms are being recognised. Those who presented many years ago with paralytic Polio are finding their lives becoming increasingly more difficult due to the long-term effects of that incident. The survivors, for that is how they classify themselves, thought they had fought and won the major battle only to find that there is always more than one battle to be won in a war. The trouble is that many are ill-equipped to fight the next battle after such a long number of years since they were called to arms the first time.

Added to that, Irish society in general believes that Poliomyelitis has gone away rather than just being held at bay through effective vaccination programmes – although in itself the vaccination has been proved on rare occasions to cause the disease itself. In this way, the needs of an ageing post-paralytic Polio population have been ignored or at best forgotten.

The results of this survey clearly demonstrate through analysis and comment garnered from around 50% of the PPSG membership (2002) that there is increasing hardship in medical, physical and socio-economic terms. These issues have to be addressed as a matter of urgency if what may be seen now as a problem, is not to become a crisis amongst a potential of perhaps in excess of 3000 members of Irish society.

The most pressing need is for Poliomyelitis to be recognised as a long-term neurological disease, just like Multiple Sclerosis and Muscular Dystrophy. The fact that it has a plateau phase lasting in some cases decades is irrelevant. A reaffirmation by Government of a statement made by an Officer of the Department of Health (meeting PPSG/DoH 10 June 1997) that LEP stems from post paralytic Polio is essential, as is the need for recognition of the cost of disability and assistance with that cost.

A modern human and humane society by its very definition has to look after the most vulnerable members of that society. These are the very young, the old and those who through no fault of their own have been visited by affliction, disease or accident. Surely, some €5,500 per person over the next 5 years is not too high a price for society to give quality of life to those with LEP?

Due to vaccination, better sanitation and hygiene education in Ireland, the Polio Survivor and those with LEP are a "dying breed". Let us ensure that the "demise" of the Polio generations in Ireland is made as comfortable and dignified as possible and make the ending happier than the beginning.

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RECOMMENDATIONS

The recommendations arising from this report are that:

1. Poliomyelitis be recognised by Government as a Long Term Neurological Illness and be included on the Long Term Illness List, in the same way as others, i.e. Multiple Sclerosis, Muscular Dystrophy.

2. An individual who has experienced a paralytic episode of Poliomyelitis and has been diagnosed with LEP/PPS be entitled, in her/his own right in the first instance, to a Medical Card.

3. The Department of Health and Children establishes multi-disciplinary centres of excellence in the diagnosis, management and treatment of LEP at Beaumont Hospital, Dublin, Cork University Hospital & University College Hospital, Galway.

4. Such centres of excellence contain an advisor from the PPSG, funded by statutory authorities, to advise on rights and entitlements to benefits and allowances.

5. Each and every Community Care Area (or successor body) has, at least, one Occupational Therapist and/or Physiotherapist trained in LEP and its management.

6. Those in receipt of aids and appliances be given full and proper training in their use.

7. Benefits relating to mobility are not linked to the age of the applicant or recipient.

8. Benefits relating to electricity, gas entitlements be given to all those in receipt of a clinical diagnosis of LEP/PPS, regardless of age.

9. Public servants dealing on a one to one basis with applicants or recipients of State derived benefits, allowances and grants, should be given disability awareness training.

10. The Department of Enterprise launches an investigation into the pricing differential of aids and appliances in Ireland compared to neighbouring EU countries.

11. The Post Polio Support Group establishes a peer support/counselling network.

12. The Post Polio Support Group seeks funding from statutory agencies for a national awareness programme on LEP and that a survey be commissioned to study the effects of LEP on asymptomatic Polio Survivors.

13. The Post Polio Support Group extends its international links to disseminate the findings and recommendations of this survey.

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DEFINITIONS OF IMPAIRMENT, DISABILITY AND THE LATE EFFECTS OF POLIO

1. Impairment

Impairment is the functional limitation within the individual caused by physical, mental or sensory factors (Gooding, 1994).

2. Disability

The loss or limitation of opportunities to take part in the mainstream of the community on an equal level with others due to physical or social barriers (Barnes, 1994).

3. Late Effects of Polio (LEP)

This is defined as the degenerative effect of the neurological system following a period of stability after an incidence of paralytic Polio. The effects, although neurological in source, demonstrate themselves mainly in physical symptoms, i.e.:

- severe pain in muscles and joints
- lack of strength, with increased muscle weakness and extreme fatigue
- respiratory difficulties, often with problems related to sleep
- severe intolerance to the cold
- decline in ability to walk or carry out customary daily activities

Commentary:

The assumption used in this report is that, whilst it is agreed that some people have impairments, it is not these impairments that "disable" them. Rather, it is the barriers and attitudes, that exist to separate them from the rest of society, which disables them. The fact that a person is unable to walk is not the problem – the problem is the inaccessible shops, social facilities, colleges, housing, transport and discrimination in employment. People with disabilities call this the "Social Model of Disability". This model states that if these barriers, which prevent people with impairments from participation on equal terms, were removed then "disability would not exist".

INTRODUCTION

POLIO

Polio has been with us for a long time – the earliest recorded descriptions are from some 3000 years ago in Egypt (Browns University, USA, Polio 2000 - History). However, it was only much later that the world experienced the epidemics that appeared in the early to middle Twentieth Century. These were brought about by many factors, mostly sociological, in that society's infrastructure developed. This was especially true regarding the supply of drinking water and sewage facilities, for Poliomyelitis is more of a disease of a developing society rather than the under developed.

The Poliovirus "enters a susceptible host in contaminated drinking water or through contact with contaminated surfaces, such as unwashed hands. After passing through the stomach, the virus reaches the intestine, where it establishes itself in the cells of the intestinal lining (the "gut mucosa"). There, it infects cells and replicates. In most cases, this results in a transient, self-limiting diarrhoea, or it may be completely asymptomatic. Unfortunately, the virus is not always so benign" (Browns University, USA, Polio 2000 – Pathogenesis).

In approximately 1% of infections (Browns University, USA, Polio 2000 – Pathogenesis), the virus spreads to the nervous system, eventually reaching the motor neurones and causing paralysis and, in extreme cases, death (12% in the American outbreak of 1952 (Halstead, 1998)). Dr Hardiman, Consultant Neurologist, Beaumont Hospital Dublin, in her opening address to the Post Polio Support Group (PPSG) Conference on 12 March 1999, said that, of the many hundreds that become infected with the virus, most only experience flu like symptoms. However, 1% would go on to develop the acute form of the disease. Hardiman (1999) went on to state that the World Health Organisation says "for every 1 case of confirmed acute Polio diagnosed there are 100 + more who have been infected and therefore it is classed as an epidemic".

POLIO IN IRELAND

There has never been an accurate figure of how many people had developed the acute phase of the disease, nor estimates of how many had the asymptomatic (non-paralytic) version. In Ireland, following work in 1996 by Julian Hart of Trinity College, Dublin, at the request of the PPSG, a figure of some 7,500 acute case survivors in Ireland was derived. The best international estimates to date have come from work conducted in the USA in 1987 where responses to the National Health Interview Survey by the National Center for Health Statistics calculated that there were 1.63 million Polio Survivors at that date. Halstead (1998) estimated that 5 – 10% of that population had died thus calculating that there were 270 surviving acute cases per 100,000 of population.

Ahlstrom et al (1993), in their Swedish paper, derived a figure of 186 per 100,000 of population. An Edinburgh University survey of Lothian (Pentland et al, 1999) derived a figure of 200 per 100,000 of population. The Lothian survey referred to a Norwegian study (Gilhus, 1998) that had derived a figure of some 250 per 100,000 of population.

Therefore, taking these incidence figures and extrapolating them onto an Irish population of some 3.9 million (CSO 2002 Census) it can be demonstrated that there could be between 7,200 and 10,500 acute Polio Survivors in the community.

LATE EFFECTS OF POLIO (LEP) IN IRELAND

Medically, for many years, Polio was thought of as a static, non-progressive neurological disorder. This gave rise in many countries, including Ireland, to the thinking that it should not be defined as a long-term illness. Then in the 1970s "reports began to surface that people who had recovered from paralytic Polio decades earlier were developing unexpected health problems such as excessive fatigue, pain in muscles and joints and most alarming of all, new muscle weakness" (Halstead, 1998). So, in the 1980s, the terms Post Polio Syndrome (PPS) and Late Effects of Polio (LEP) came into use in the medical profession. (*In the body of this report the abbreviation LEP will be used throughout.*)

However, it turns out that it is not a new disorder at all, as Halstead (1998) states "It was described in French Medical literature in 1875, and then, as often happens in medicine, it was forgotten; over the next 100 years approximately 35 reports on post Polio weakness were published in the medical literature". Studies published by the Government of the State of Queensland, Australia (1998) suggest that the time period between the acute Polio and onset of LEP range from 8 to 71 years, the average interval being around 35 years.

Although all of these studies are recent, in research terms, they have all been superseded, at least in part, by one critical factor. All the derived figures have excluded persons with a history of non-paralytic Polio. Historically there has been a medical tendency to require a history of acute paralytic Polio before any diagnosis of LEP would be even considered. Papers that were written in the 1950s do not support this tendency. Salter (2000), in his paper Post Polio Population Statistics – A Review, reported "evidence of a level of neuronal damage by the Polio virus that does not present any clinical signs of paralysis at the time of infection". Include these in the above estimates and minima and maxima figures of 23,200 to 26,500 of Polio Survivors in the Irish population are derived.

Not all of these are expected to develop LEP. No one knows how many paralytic Polio Survivors have LEP, let alone the asymptomatic cases. Some studies suggest 40% of paralytic cases will develop LEP (Halstead, 1998); other studies have ranged from a low of 22.4% to a high of 60% (Government of the State of Queensland, 1998). Field (1995), in his United Kingdom based National Survey of Polio Survivors, states "Between 20 – 40 years after their original infection by Polio approximately 77% of survivors experience new symptoms". Therefore, if a mid-point is taken, say 40%, it suggests that the number of Irish paralytic Polio Survivors who will experience LEP ranges from 3,000 – 4,200.

Research into this condition is currently being undertaken in Ireland and internationally. This research is primarily clinically based, studying the physiological symptoms. At this stage, there is no known cure.

POST POLIO SUPPORT GROUP

The Post Polio Support Group (PPSG) originated in 1993 when it was realised that Polio Survivors were facing a second disabling condition of which very little was known in Ireland. This condition – now known as the "Late Effects of Polio" (LEP) or "Post Polio Syndrome" - is internationally medically recognised (Ahlstrom et al, 1993, Falconer, 1999). The PPSG has been extremely active over the last few years in raising awareness about the increasing number

of Polio Survivors who are suffering LEP. The numbers of people contracting Polio in Ireland peaked in the 1950s; this has since reduced to single figures through the introduction of an effective vaccination programme. The age range of PPSG members is from mid-30s to old age, with the average now in the 50 to 60 years age bracket. There are progressively more survivors needing assistance who are suffering symptoms. This is likely to continue as the existing Polio Survivor population develops problems.

The concern of the PPSG is now to ensure that appropriate and timely support is available to meet the future needs of survivors. Planning for the availability of such support will be enhanced by better quality accurate information about the needs of individuals and their circumstances. It will also be enhanced by investigation of the methods of cost-effective delivery of support e.g. preventative programmes dealing with early symptoms rather than more costly acute, clinical services needed where rapidly advancing symptoms are unchecked.

It was against this background that the PPSG commissioned this survey into how LEP affects the Polio Survivor in all aspects of their lives.

QUOTATIONS FROM SURVEY RESPONDENTS

Polio

"It was never diagnosed but both brother and sister lost their walk later in life."

"Mother noticed that I was walking a little unsteady as if I had a stone in my shoe."

"My Polio was contracted when my daughter was given the sugar lump at the clinic. It was her booster shot."

"I get tired all the time."

"Does the Health Service ever follow up Polio victims? Sought files under Freedom of Information – told none exist."

Transport

"Difficulty with transport to and from work."

"Why don't they pay mobility allowance to people over 65? Free travel isn't much good to folk in a wheelchair, particularly in the country."

"I would be interested in being assessed for a scooter so that I could go to Mass on my own!"

Finances

"Very difficult to survive on disability benefit."

"Main worry is lack of money, due to small pension allowance."

"The hidden costs are high."

"The cost of disability with regard to everyday living is more expensive, e.g. house maintenance, gardening, and window cleaning – have to be paid."

"Cannot think of the future as I am trying to survive basic worries – if the weather gets cold, will I have enough money for heating?"

Employment

"Considered unemployable – so started printing as a Sole Trader – then partnership, then Limited Company. About 38 years in total."

"Got 8 Honours in the Leaving Cert. and was accepted for training as a National Teacher but was rejected by their medical doctor!"

Attitudes

"Feeling of shame when home from Cappagh Hospital and ignorance of people about illness. No-one ever explained that it was not the fault of the person suffering from the illness."

"It's clear I have an impairment which is my condition. My disability is my society, which has disabled me through attitude, communication and access ..... I would not see my condition as an illness."

Assistance

"Fiercely independent – would not even consider having home help!"

"(I have) .... a bit of a difficulty accepting help, as I would rather do it myself. But I am willing to sacrifice pride to keep the place clean."

"I believe the only Nursing Home I want is my own home with all my things around me."

"There's no point (...seeking assistance). Forms are not geared for what we need."

The Future

"I am being very positive and don't think my condition will deteriorate much."

"I hope to be much the same as I am now. If I am, I'll be lucky."

"I will try to stay independent and cope. Family support is vital."

"I try to maintain a positive attitude and try not to be negative, I'm fortunate to have a great support network around."

"Will have to be careful in what I can do – I'm always trying to exceed personal limitations."

"Have some concerns about the future. At present, rely primarily on husband for assistance. What happens if he can't help?"

Social

"It's the social side of it, social and emotional side of it ..... you don't necessarily know what you need emotionally."

"Things are just gradually going down and I'll just have to adjust to managing it."

"Peer support is very important as it is non-judgemental compared to general support groups."

"Why do people with disabilities always have to fight for their entitlements?"

METHODOLOGY

The results of this survey needed to be as accurate and as qualitatively thorough as possible to give the best possible chance for accurate forecasting of the future needs of the PPSG membership. Therefore the survey was conducted through the medium of a respondent completed questionnaire, followed up by a further interview and questionnaire completed by a qualified Occupational Therapist (OT) in the respondent's home. (It was found, at both pilot stage and survey commencement, that difficulty was experienced in securing the services of suitable and available Occupational Therapists to assist. This was particularly so in the Dublin area.)

Additional information to that on the survey forms was gathered by the Occupational Therapists whilst conducting the interviews, and this is mostly reported in the section dealing with Additional Information. This added a further useful dimension to the more formal and quantitative information collected from the questionnaires.

The Client Group

The Polio Survivor membership of the Post Polio Support Group (PPSG) at the time of the survey (2002) in the Republic was 390 – around 5% of the total estimated Polio Survivor population. In August 2003 it stands at over 450. Many more survivors, who are not members, are in regular contact for information, and the PPSG has members living in Northern Ireland and overseas.

Polio Survivors live in the community at large and have integrated well into society. Many have achieved success and distinction in their chosen professions and vocations, despite a disability left from the disease, generally contracted in their childhood. The energy and vigour to which many survivors go about achieving their goals is impressive. For some, there is now a fear that LEP will rob them of that hard-earned independence they gained initially.

This had consequences for the successful identification of the Respondent Group and for this survey specifically. For example, survivors currently experiencing a series of new symptoms – muscle pain, fatigue, tiredness, increased susceptibility to cold – may be misdiagnosed, particularly if they have not registered their Polio status with their General Practitioner (GP).

Also, survivors who are continuing with "life as usual" are not likely to welcome the news that LEP symptoms may be possible at some time in the future. Therefore, they may be unwilling to be identified as a Polio Survivor.

These factors, along with the fact that many GP's are unaware of LEP, emigration and immigration of Polio Survivors, reluctance to volunteer health information, and poor post-war records, mean that a complete population count of Polio Survivors will always be extremely difficult. The Irish survivor population, mentioned in the introduction, was determined for the PPSG with the assistance of a Trinity College Dublin statistician using death rate figures, an internationally accepted methodology.

Sampling Technique

During 2002, a letter was sent to all 390 members of the PPSG who had suffered an incidence of paralytic Polio and who lived in the Republic of Ireland, asking if they would be willing to take part in a survey regarding LEP - some 230 replied. The final take up was 225 (57.7%). Therefore, the sample that entered the survey cannot be said to be truly scientific as it was self-selecting. However, the PPSG membership is approximately 1/3 male and 2/3 female and this split is reflected in the respondents.

It is also acknowledged that this grouping has a particular bias in terms of loss of ability, i.e. most are currently suffering symptoms of LEP and have contacted PPSG for support. Therefore, the sample probably contains a higher ratio with those with LEP than would be the international experience.

Geographic Spread

At the time of initial contact the total survivor membership of the PPSG was distributed as follows:

175	(45%)	Eastern Region (ECAHB, SWAHB, NAHB, NEHB, MHB)
155	(40%)	Southern Region (SHB, SEHB, MWHB)
55	(14%)	West and North West Regions (WHB and NWHB)
5	(1%)	Northern Ireland and overseas

The Questionnaire

In parallel to the membership being invited to participate, a pilot questionnaire was devised that looked at all aspects of those with LEP. This questionnaire was tested on 13 members and the results analysed and surveying process examined. This resulted in some minor modifications in detail but not in principle.

Aspects of information covered in the Survey Questionnaire were:

Past condition – over the last 5 years

Present condition

- Current Use of Services
- Current Use of Aids and Appliances
- Current Use of Respite Care

Future condition – over the next 5 years

- Need for Services
- Need for Aids and Appliances
- Need for Respite Care

Daily Tasks

- Mobility
- Transfers
- Daily living tasks
- Home making
- Community Living Skills

Profile & Other Information

- Accommodation
- Primary Carer
- Education
- Household Income
- Car Tax Relief
- Employment
- Working Arrangements

Polio Medical History

GP Services

Approach

The method of data collection involved two parts – an initial postal survey to be collected by the interviewer upon visiting the respondent and then an assessment of each respondent by the OT. This approach was chosen to:

1. Increase the return rate – it was thought that many people might have had difficulty completing a written survey due to their physical condition or symptoms.
2. Improve the quality of data collected – future needs assessments and prognosis.
3. Develop trust with the interviewer that shared information would be kept secure.

Interviewers

All of the interviews were conducted by professional Occupational Therapists. This was for three reasons:

1. To assist with a professional prognosis of future needs.
2. To increase credibility of the survey, the integrity of the information and therefore trust with the respondents being surveyed.
3. To give respondents an opportunity for a professional assessment of their needs and an opportunity for some advice.

Needs of the Respondents

All participation was on a strictly voluntary basis.

The nature of Polio Survivors and the symptoms of LEP meant that it was important that the survey methodology met the needs of those being surveyed as much as it did those conducting the survey.

Respondents were interviewed at a time and place suitable for both parties; preferably, this was at the home of the respondent. Participation was on a strictly voluntary basis – respondents were asked for consent in writing and guaranteed security of the data collected and anonymity.

Time Period

All the above factors – professional interviews conducted in a wide range of locations at times suitable to the respondents - meant that collecting quality data for the survey was both time and cost intensive. It took 6 months to collect and collate the results from all the respondents ending in January 2003. The analysis of that data and preparation of the report has taken a further 10 months.

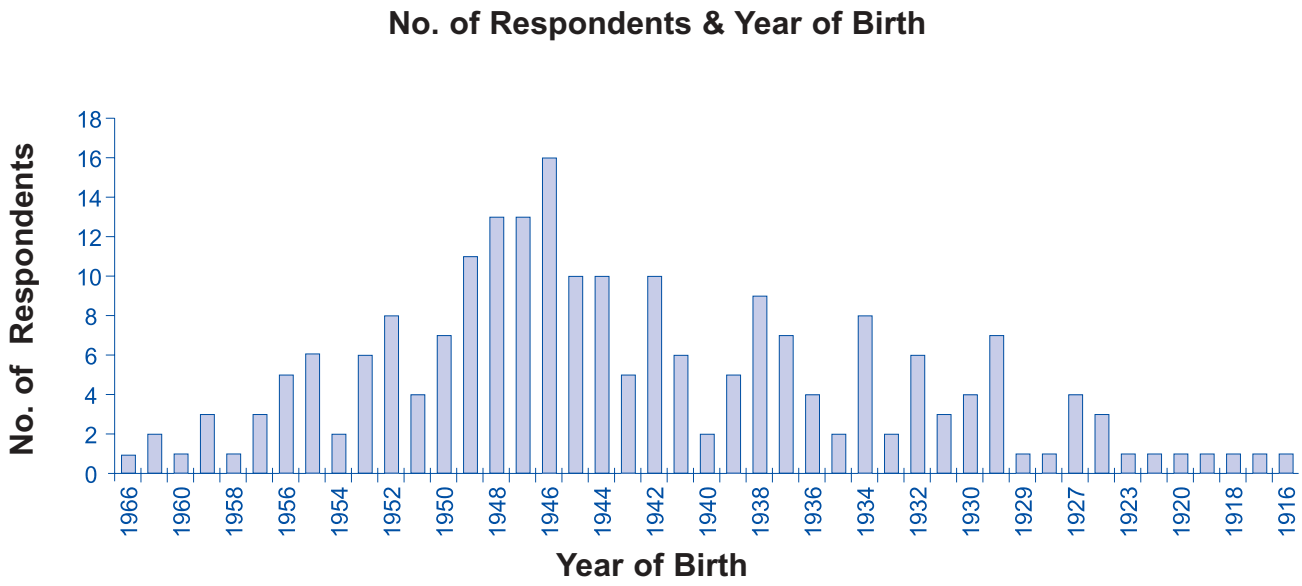
Note: *Initially the survey covered 225 respondents. However since completion, a respondent has died and, in common with normal research practice, the data relating to the deceased has been excluded from the findings.*

QUESTIONNAIRE & INTERVIEW FINDINGS

Profile of Respondents

The most defining feature about the respondents to the survey is that there is no typical profile. The only things the respondents have in common are the criteria of living in the Republic of Ireland and having had an incidence of paralytic Polio at some point in their medical history.

Out of the 224 respondents 78 (35%) were male to 146 (65%) female. Whilst this does not represent the demographic split of the country in general, namely 49.7% to 50.3%, respectively (CSO Census 2002), it is a true reflection of the membership split within the PPSG. (The gender spilt amongst people with disabilities is 47% male to 53% female (CSO Census 2002).)



The average age of respondents was 60 years old, against a national average of 35.1 years (CSO Census 2002). The actual ages of respondents ranged from 37 to 87 years of age. Some 60% of respondents were under the age of 5 when they contracted Polio.

The PPSG has a membership distribution across the whole country as can be seen from Table 1 below. This shows the geographic distribution shown against the national population in the form of a percentage differential.

Table 1 - National population Distribution v PPSG Membership & Survey Distribution

Province or County	Population Census 2002	% of State pop.	Number of PPSG Members 2003	% of PPSG Members	Difference State v. PPSG %	Survey Respondents	% Survey Respondents
STATE	**3,917,336**	***100***	**444**	***100***	**-**	**224**	***100***
Leinster	**2,105,449**	***53.8***	**248**	***55.9***	***2.1***	**129**	***57.6***
Carlow	45,845	*1.2*	10	*2.2*	*1.0*	6	*2.7*
Dublin	1,122,600	*28.7*	140	*31.5*	*2.8*	69	*30.8*
Kildare	163,995	*4.2*	14	*3.2*	*-1.0*	10	*4.4*
Kilkenny	80,421	*2.1*	6	*1.4*	*-0.7*	3	*1.3*
Laois	58,732	*1.5*	13	*2.9*	*1.2*	9	*4.0*
Longford	31,127	*0.8*	2	*0.5*	*-0.3*	0	*0*
Louth	101,802	*2.6*	7	*1.6*	*-1.0*	4	*1.8*
Meath	133,936	*3.4*	10	*2.3*	*-0.9*	4	*1.8*
Offaly	63,702	*1.6*	9	*2.0*	*0.4*	6	*2.7*
Westmeath	72,027	*1.8*	10	*2.3*	*0.5*	6	*2.7*
Wexford	116,543	*3.0*	13	*2.9*	*-0.1*	6	*2.7*
Wicklow	114,719	*2.9*	14	*3.2*	*0.3*	6	*2.7*
Munster	**1,101,266**	***28.1***	**130**	***29.3***	***1.2***	**65**	***28.9***
Clare	103,333	*2.6*	23	*5.2*	*2.7*	16	*7.1*
Cork	4448,181	*11.4*	62	*14.0*	*2.6*	27	*12*
Kerry	132,424	*3.9*	9	*2.0*	*-1.9*	6	*2.7*
Limerick	175,529	*4.9*	17	*3.8*	*-1.1*	6	*2.7*
Tipperary	140,281	*3.6*	8	*1.8*	*-1.8*	5	*2.2*
Waterford	101,518	*2.6*	11	*2.5*	*-0.1*	5	*2.2*
Connacht	**464,050**	***11.8***	**51**	***11.5***	***-0.3***	**24**	***10.7***
Galway	208,826	*5.3*	15	*3.4*	*-1.9*	6	*2.7*
Leitrim	25,815	*0.7*	2	*0.5*	*-0.2*	0	*0*
Mayo	117,428	*3.0*	16	*3.6*	*0.6*	7	*3.1*
Roscommon	53,803	*1.4*	7	*1.6*	*0.2*	4	*1.8*
Sligo	58,178	*1.5*	11	*2.5*	*1.0*	7	*3.1*
Ulster (part)	**246,571**	***6.3***	**15**	***3.4***	***-2.9***	**6**	***2.7***
Cavan	56,416	*1.4*	5	*1.1*	*-0.2*	0	*0*
Donegal	137,838	*3.6*	8	*1.8*	*-1.6*	5	*2.2*
Monaghan	52,772	*1.3*	2	*0.5*	*-0.8*	1	*0.4*

Source: Central Statistics Office, Census 2002 and PPSG office

Table 2 below shows the distribution of survey respondents by Health Board:

Table 2 – PPSG Survey Respondents by Health Board Area

Health Board	PPSG Members 2003	% of PPSG Members	PPSG Respondents 2002	% Survey Respondents
	444	100	224	100
Eastern Region Health Authority	167	37.6	85	38.2
East Coast Area Health Board	38	8.6	21	9.8
Northern Area Health Board	65	14.6	28	12.4
South Western Area Health Board	64	14.4	36	16.0
Midland Health Board	35	7.9	21	9.3
Mid-Western Health Board	41	9.2	23	10.3
North Eastern Health Board	24	5.4	9	4.0
North Western Health Board	21	4.7	12	5.3
Southern Health Board	71	16.0	33	14.7
South Eastern Health Board	47	10.6	2.4	10.7
Western Health Board	38	8.6	17	7.6

Source: PPSG Office

As can be seen from Table 2 above, the Post Polio Support Group has a wide geographical membership base that reflects, in the main, the general demographics of the Republic of Ireland. This reflection has been carried through into the spread of those who responded to the survey.

In this manner it may be concluded that LEP is a countrywide phenomenon and not just confined to one area or sociological grouping.

Table 3 – Age at time of Polio diagnosis

Age Group	No.
0 – 5	132
6-11	39
12 - 15	22
16 – 20	10
21 – 25	7
26+	8
Don't know	5
Never properly diagnosed	1
Total	224

Medical History of Respondents

The disease Poliomyelitis cannot be accused of discrimination in the way it infects. It does so without fear or favour and affects all segments of society regardless of age, sex, occupation or social standing. Poliomyelitis had a rather more common name in the past, Infantile Paralysis, and that best describes where it hit hardest and with the most devastating effects. Out of the 224 survey respondents 132 (60%) were under the age of 5 when the disease struck.

Interestingly, 155 (69%) of respondents stated that the onset of the disease was very rapid. However, some caution must be placed on this figure due to the young age of most at the time of onset, but there is some evidence to suggest that their opinion is not unfounded.

Table 4 – Age at diagnosis of LEP

Age at onset of LEP	No.
35-39	1
40-44	9
45-49	17
50-54	15
55-59	7
60-64	8
65-69	4
70-74	2
75-79	0
80-84	3
Age not stated	1
Total	67

For the purposes of the survey and due to the self-selection process of respondents, all those participating have had an incidence of paralytic Polio. The way that paralytic Polio affects those infected varies from one individual to another but, in general, there is a period of paralysis, recovery, plateau and then the progression into LEP in some 40% of cases (Halstead, 1998).

The paralytic effects at initial and subsequent stages are shown in Table 5 below:

Table 5 – Extent of weakness/paralysis – initial & subsequent

Extent of weakness/paralysis	Initial Paralytic Phase No.	Subsequent Recovery Phase No.
No paralysis	1	9
One leg	113	131
Both legs	93	67
One arm	45	45
Both arms	39	22
Two or more limbs/trunk	58	33
Chest – difficulty breathing	42	16
Swallowing difficulties	14	5

Note: Many respondents reported more than one area affected and this accounts for totals greater than the number of respondents in the survey.

It can be seen from Table 5 above, in the majority of cases respondents reported that they had recovered some function following the initial paralytic phase.

As stated in the introduction, the Late Effects of Polio (LEP) can occur 8 – 71 years (Government of the State of Queensland, 1998) after the initial paralytic phase. No one knows for sure what the time span between contraction of asymptomatic Polio and onset of LEP may be, but research would tend to suggest that the time span is probably similar (Government of the State of Queensland, 1998).

It is also apparent that those who were apparently unaffected, i.e. siblings or other close family members of respondents, who presented with paralytic Polio, can also have been affected (Falconer, 1999). Of the survey respondents, 25 (11%) reported that these relations experienced symptoms akin to their own, although they had never been diagnosed with Polio at the time. This has implications as to whether these relations will, or have already, developed LEP.

As previously stated, all the respondents were self-selecting. However, only 74 (34%) had an actual diagnosis and, of these, 48 (68%) had all been seen at the Beaumont Hospital by Dr. Orla Hardiman, Consultant Neurologist, Beaumont Hospital, Dublin.

Table 6 – Respondents in receipt of diagnosis of LEP

Total	No	Yes	Not Stated
224	144	74	6

From all of the above, it can be seen that Polio is a long lasting and debilitating disease that can cause unforeseen effects many years after the initial paralytic stage in the form of LEP. Yet, it is not recognised in Ireland as a Long Term Neurological Illness, being perceived as being a stable condition after the initial incidence. This is manifestly incorrect and was shown to be so as far back as 50 years ago (Halstead, 1998). In consequence, a minority of the survey respondents under the age of 70 is in receipt of either a Long Term Illness List or Medical Card. As will be shown later, this is causing both distress and financial hardship to themselves, their families and carers.

Table 7a – Medical Card – all respondents

Age group of respondent	No Medical Card No.	Have a Medical Card No.
35-39	0	1
40-44	4	3
45-49	11	6
50-54	25	11
55-59	41	19
60-64	13	15
65-69	14	18
70-74	4	18
75-79	0	7
80+	0	7
Age not stated	2	0
Total	114	105

Table 7b – Respondents under 70 in receipt of Long Term Illness Card (LTI)

Age group of respondent	No, don't have LTI Card No.	Yes, have LTI Card No.
35-39	1	0
40-44	7	0
45-49	14	1
50-54	32	2
55-59	53	4
60-64	25	1
65-69	24	3
Total	156	11

Note: The survey did not explore whether those under 70 in receipt of an LTI Card may have qualified due to another condition.

General Practitioner Services

Although, in general terms, people with disabilities do not regard themselves as "sick", a General Practitioner (GP) who is aware and conversant with the disability is of great benefit. Those who have LEP, as with others suffering from neurological conditions, need it to be managed over a long number of years.

Therefore, the survey contained a section that specifically addressed GP services.

Table 8 – GP aware of Polio History

GP aware of Polio history	Total No.
Yes	183
Some	23
No	8
Don't know	4
Not stated	6

From the total of 183 (82%) who replied that their GP was aware of their history, 124 (67%) had discussed the subject of LEP with them. Yet Table 6 clearly shows that only some 74 (33%) of that number had a formal diagnosis of LEP.

Table 9 – Discussed LEP with GP

Discussed LEP with GP	Total No.
Yes	124
No	91
Can't remember	1
Not stated	8

Furthermore, only 62 (50%) of those who had discussed the subject stated that they were offered any help or advice. This may be because only 36 respondents (17%) felt that their GP practice could positively deal with LEP, with another 42 (20%) only being able to do so somewhat.

Table 10 – Advice/help offered by GP practice

Advice/help offered by GP practice	Total No.
No	135
Yes	62
Can't remember	4
Not stated	23

Respondents were asked to state what services were available through their GP. These are shown in the Table 11 below:

Interestingly, when asked to comment on the service received from their GP 138 respondents (61%) made "No Comment". (The survey did not pursue the reasons for this high rate.)

Education

Table 12 – Educational Achievement of all Respondents

Highest level of education achieved	Total %
Primary	30
Junior Certificate	20
Leaving Certificate	22
Third Level Certificate/ Diploma	11
University Primary Degree	5
University Postgraduate	7
Other	5
Not stated	1

Whether as a consequence of previous educational experiences or merely the age profile of the respondents, only 63 (28%) felt in the need of further education.

Table 14 – Further Educational Requirements

Further education requirements	Total No.
None	128
Yes	63
No comment	27
Not stated	6

Table 11 - Services available through GP

Services available through GP	Total No.
Physiotherapy	63
Communication with specialists	54
Occupational therapy	11
Counselling/psychological care	9
Alternative therapies	6
None or Not stated	121

As can be seen from Table 3 above, the majority of respondents, 171 (76%), suffered their incidence of paralytic Poliomyelitis before the age of 11 years old. It can be seen, in Table 12 below, that this had a profound effect upon their educational opportunities, with 110 (49%) never having progressed beyond Junior Certificate level.

Interestingly, when asked whether Polio had affected their education, those that responded "Yes", 100, approximates to the number who had not progressed beyond Junior Certificate, namely 110 (49%).

Table 13 – Education affected by Polio

Polio affected education	Total No.
Yes	100
No	71
Somewhat	45
No comment	4
Not Stated	4

Table 15 – Relationship between Educational Achievement & Employability under 65 Years

Level of education	Unemployed No.	Employed No.
Primary	23	21
Junior Certificate	19	16
Leaving Certificate	11	19
Third Level Certificate/Diploma	6	8
University Primary Degree	2	3
University Postgraduate	2	7
Other	5	3
Total	68	77

The educational achievement of respondents may have decided, to some extent, their suitability and chances of finding employment. Table 15 left compares attainment in education against employment status for respondents below 65 years of age at the time of the survey.

Employment

At the time of the survey, 145 (65%) of respondents were of working age out of the total participation. Of these, there is a split between those in and out of work, 77 and 68 (53% and 47%), respectively. The point where the figures diverge is the 60 – 64 year old group and, on closer examination, those in this group are predominantly female.

Table 16 – Ratio of Unemployed to Employed by Age Group under 65 Years

Age group of respondents	Total No.	Unemployed No.	Employed No.
35-39	1	1	0
40-44	7	2	5
45-49	16	8	8
50-54	36	10	26
55-59	57	24	33
60-64	28	23	5
Total	145	68	77

This shows an unemployment rate in the respondent group of 47% (68), whereas the Census 2002 statistics give an unemployment rate for all people with disabilities of 75%.

When questioned, the respondents of all age groups not in employment said that they had been out of work for the following periods:

Table 17 – Length of time out of Employment – All Age Groups

Length of time since last employed	Total No.
Not stated	1
Up to 6 months ago	7
7 months to 1 year ago	4
1 to 2 years ago	9
Over 2 years ago	88
Never been employed	11

It can be seen that the majority, 97 (82%), had been unemployed for over 1 year.

The reasons given for unemployment and the length of time unemployed, amongst 48 (49%) of those identified above, were the following:

Table 18 – Reasons given for Unemployment – All Age Groups

Reasons for unemployment status	Total %
Now too disabled	16
Retirement Age	11
Have taken early retirement	10
Engaged in home duties	7
Not Suitable	2
Full Time Education	2
Not Stated	52

Table 19 below shows the status of those who are in employment. Some respondents count unpaid training schemes and voluntary work as employment and this accounts for the discrepancy in the figures, i.e. 77 to 91.

Table 19 – Employment by Employer category

Current employment status	Total No.
Employed by company including family	53
Self employed	18
Other	10
On FAS/other training scheme	6
Self-employed – farming	4
Total	91

Table 20 below shows the work status of the respondents identified in Table 19 above. This shows that, of the 91 in "work" at the time of the survey, 60 (66%) were in full-time employment.

Table 20 – Numbers in Full, Part or Casual Work

Work status	Total No.
Full-time	60
Part-time	23
Seasonal or casual	5
Other	1
Not stated	2

Table 20 was corroborated by a question asking respondents whether their capacity to work was/is affected by LEP. This shows that 24 respondents (30%), who are engaged in part-time or seasonal work, believe that LEP does have a bearing on their working capacity.

Table 21 – Capacity to work affected by LEP

Capacity to work affected	Total No.
Yes	50
Sometimes	35
No	32
No comment / Not stated	117

The survey also examined the effect that poliomyelitis/LEP had and has on the employment prospects of respondents. Furthermore, it looked at the social aspects and employers' attitudes. Initially, respondents were asked whether they thought that having Poliomyelitis had ever caused them to lose a job and 170 (76%) thought that it had made no difference.

Table 22 – Polio caused loss of Employment

Ever lost work because of Polio?	Total No.
No	170
No Reply	19
Don't know	17
Suspect it was a factor	12
Yes	6

However, on further questioning, some respondents (in excess of the 18 (8%) in the "Yes" and "Suspect it was a factor" categories) replied as follows:

Of the 77 respondents, under the age of 65, who are in employment, 50 (65%) declared that their employer knew about their Polio Survivor status, while the remainder had not disclosed the fact. The reasons for non-disclosure given by 13 respondents (17%) are shown in Table 24 below:

Table 23 – LEP caused loss of Employment

Reasons lost employment	Total No.
LEP interfered with ability	18
LEP led to poor attendance	4
Transport to and from work	2
Other	2

Table 24 – Reasons Employers not aware of Polio status

Reasons employer not aware	Total No.
Don't feel the need to	9
Fear will affect promotion	4

More than half of those under 65 years old in work, 44 (57%), declared that their working environment was supportive. No respondent said that they had met hostile or non-supportive attitudes within the working environment. The vast majority of respondents in employment, 55 (66%), found no difficulty with access to their working environment.

It is worth noting that the gender split of those in employment fits the general overall profile of respondents, i.e. 26 (34%) male, 51 (66 %) female. Therefore, it cannot be argued that any of the employment statistics and findings are distorted through the traditional gender differential of the male working whilst the female stays at home.

This, in part, may be because, within those who are in employment, more females than males live on their own, 15 (27%) female to 6 (22%) male. Therefore, it could be that the proportion of working females within the sample is higher than the national average due to economic necessity. However, this has to remain a matter for conjecture, as it was not followed up within the survey.

Employment, and the lack of it, has a profound bearing on the quality of life that can be enjoyed by those with LEP. This is especially true for those who have to rely either on a pension or on some other form of benefit.

Finances

Respondents were asked to state their monthly household income (not just personal income) and to rate this against that how well they were able to manage. (Note: 9 Respondents did not complete this section. Therefore, the percentages are calculated on 205 not 224.) As can be seen from the table below, 114 (56%) said they could only manage with some or great difficulty. 91 respondents (44%) said they could manage without difficulty, but it should be noted that this category contained the highest earners, 61 (30%) of the total sample, declaring a household income of over €24,500 per annum. However, worryingly, 63 (31%) of respondents appear to be living at or below the equivalent of the statutory minimum wage level of €6.35 per hour (experienced Adult worker – August 2003).

Table 25 – Ability to Cope by Monthly Income Group

Monthly household income €	Total No.	With great difficulty %	With some difficulty %	Without difficulty %
Less than €509	19	32	53	16
€509 - €1,016	44	18	61	21
€1,017 - €1,524	44	11	46	43
€1,525 - €2,031	30	7	50	43
€2,032 - €2,539	18	0	50	50
€2,540 - €3,047	19	0	26	74
€3,048 - €3,555	5	0	60	40
€3,556 - €4,063	6	0	50	50
More than €4,063	13	0	0	100
Not sure	7	0	14	86
Total – Nos.	***205***	***21***	***93***	***91***
Total - %	***100***	***10***	***46***	***44***

Note: *In order to calculate the number at or below the statutory minimum wage level, the working week was assumed to be 39 hours per week on 52 weeks a year, i.e. [((39 x €6.35) x 52) /12 =] €1,073 per calendar month gross. It should further be noted that the figures reported by respondents are net of all deductions, i.e. Income Tax, PRSI, etc.*

When the number of respondents in receipt of benefit is examined it is hardly surprising that so many find difficulty in making ends meet, for some 153 (68%) receive benefit and in some cases more than one type. Amongst the respondents in employment 12 receive benefits.

Respondents, although voicing some concerns about being able to cope in old age, demonstrated that they have provision in place, in the main, although the 34 (15%) who replied they did not know what provisions there were, give rise to concern.

Note: *The ratio between the genders is, once again, in general terms, a reflection of the 1/3 to 2/3 male/female split of total respondents.*

Table 26 – Retirement Provisions & Benefits

Eligible Retirement Provisions & Benefits	Total No.	Male No.	Female No.
Old Age Contributory Pension	90	35	55
Private Pension	61	24	37
Old Age non-contributory Pension	35	8	27
Other State Payment	14	3	11
Invalidity Pension	10	3	7
Don't know	34	11	23

Note: *The total exceeds 224 as some respondents will be or are in receipt of one or more type of retirement provision or benefit.*

Those with LEP, in the same way as many other disabilities, have additional costs that are incurred due to their disability, in comparison to the standard population. The fact that LEP is progressive means that those costs are going to rise in the years to come. At the time of the survey, the most frequently reported items of additional expense, as shown in Table 27 below, were communications and heat and light. These accounted for nearly half regardless of income group.

Table 27 – Abstract of Additional Costs attributed to LEP

Additional Costs	Total No.
Personal Transport	141
Public Transport incl. Taxis	55
Telephone (excl. mobile)	139
Heat & Light	162
Clothing	132
Footwear	142

As can be seen from Table 27, 25% of additional costs is accounted for by transport. Under Revenue Commissioner Regulations (Vehicles for People with Disabilities – Tax Relief Scheme, VRT 7, March 2002), persons with a Primary Medical Certificate are entitled to certain concessions, i.e. 0% VRT and full VAT rebate on new cars, rebate of duty on fuel for cars etc., subject to certain criteria being met. Therefore, respondents were asked whether they had applied for or were in receipt of these concessions.

Note: *A full range of additional costs, broken down by income group, is detailed in Appendix A.*

Out of all the respondents, 114 (51%) had applied for the concessions. Of these, 13 (12%) applicants had been refused; 9 (4%) of these had appealed and, at the time of the survey, 6 (3%) of those had been unsuccessful with the other three being successful.

Table 28 – Applied for Tax Relief on Vehicle

Applied for Tax Relief on Vehicle?	Total No.
Yes	114
No	67
No - I don't have a car	18
No – didn't/don't know about	17
Not stated	8

Verbal evidence to the OT's would suggest that, in common with other national schemes administered locally, there are discrepancies in both the application and implementation of the Primary Medical Certificate procedure. One respondent reported that, when interviewed by the Public Health Doctor for verification of application, it was initially refused on the grounds that the applicant could not be paralysed in both legs as he was standing. This was despite the fact that the respondent was wearing full-length callipers on both legs and was supported by auxiliary crutches and lacked reflex action in the lower limbs.

It is apparent that both the terms of reference and criteria for eligibility to the Primary Medical Certificate should be reviewed and implemented on a national basis.

Domestic Arrangements

The table below reflects the domestic arrangements of respondents. The figure for living alone, whilst over a quarter of respondents (27%), seems to be broadly in line with national trends (22%, CSO Census 2002).

Table 29 – Living Arrangements

Living arrangements	Total No.
With spouse/partner + child/children	75
Living alone	59
With spouse/partner - no children	53
With sibling(s)	11
With child/children only	9
With one parent	5
With friend(s)	4
With other family	2
In full-time residential	3
Not stated	3

When respondents were queried as to whether they had a primary carer, a surprising 137 (61%) replied in the negative. Whether that is because they do not need one or because they see the carer role as being an integral part of domestic life is not clear. The remainder defined their primary carer as shown in Table 30 below (which is also shown by age grouping of the primary carer). Only 15 primary carers do not live with the person they care for.

Table 30 – Relationship with Primary Carer by Carer Age Category

Relationship with primary carer	Carer's Age 21 – 40 No.	Carer's Age 41 – 60 No.	Carer's Age Over 60 No.
Husband/wife/partner	3	29	29
Mother/father	0	0	2
Son/daughter	1	3	0
Other relative	0	2	4
Neighbour/friend	2	3	2
Employer/employee	0	1	0
Other	2	1	1

As can be seen, the majority of carers are in the higher age range which, in turn, will create problems as, through the ageing process, in time they will not be able to deliver the quantity of care required. Indeed, it is found that carers themselves are more susceptible to ill health, i.e. stroke, stress, due to the very process to which they are devoted, namely caring for a loved one (The Alzheimer Society of Ireland).

A recent report for The Princess Royal Trust for Carers (October 2003) in the United Kingdom found that "Around two thirds of carers who provide for more than 50 hours per week say their health has been affected". It goes on to say that "40% of carers themselves have some form of illness or disability" and that the current value of support given by carers is around the same level as the total UK spending on health - £57 billion in 2001-2002.

The amount of care needed varies from one individual to another but respondents reported the following was required each week:

Table 31a – Carer Hours per week

Hours per week provided by carer	No.
1 to 5 hours	13
6 to 10 hours	8
11 to 20 hours	13
21 to 30 hours	18
31 to 40 hours	2
41+ hours	28

It is further apparent, from Table 31a, that, as in the UK, the carers of those with LEP are making an enormous, yet hidden, contribution toward the State coffers. For example, if an average carer rate of €10 per hour is assumed (Midland Health Board, July 2003), and care is required for, say, 22 hours per week (the mean average of the table above), then that contribution amounts to some €11,400 per year per carer. Over the whole of the sample, this comes to a figure of some €950,000 per annum.

If one assumes that the trend of carers is carried across the lower end of national pool of those with LEP, i.e. 3000, this increases to a staggering €12.65m of hidden contribution to the State coffers.

Furthermore, this care is not one-off but continuous and is needed at both regular and irregular intervals, according to the particular requirements of those with LEP.

This can best be demonstrated from the responses regarding frequency of demand that were given:

Table 31b – Frequency of Care Demand

Hours per week provided by carer	Once during the day No.	Occasionally during the day No.	Frequently during the day No.	Twenty- four hours per day No.	Total No.
1 to 5 hours	3	7	0	0	10
6 to 10 hours	3	3	0	0	6
11 to 20 hours	0	4	8	0	12
21 to 30 hours	1	7	10	0	18
31 to 40 hours	0	1	1	0	2
41 + hours	0	1	10	18	29

Table 32 – Range of Carer Duties

Type of care provided	Total No.
Domestic, social and personal	37
Domestic only	22
Domestic and social	20
Domestic and personal	5
Personal care only	2

The ranges of duties that the carers encompass are many and varied, but can be best defined as falling into the following categories:

As can be seen from Table 32, the most frequent type of care provided encompasses the whole life of the respondent with LEP, from the most intimate necessities of life through to those that encompass the social aspects. In one form or another, 37 (43%) deal with domestic, social or personal care. Without this care, many of the respondents would be unable to lead a life in the community in general and, perhaps, would be forced into institutions. This would involve the State in possible Subvention payments under the Health (Nursing Homes) Act 1990.

Housing

During the interview section of the survey, the Occupational Therapists asked the respondents whether they could examine their living accommodation. This was, in part, to ascertain present and future needs, as well as to judge the adaptations that were already in place. Understandably, given the philosophy that has surrounded Poliomyelitis over the years of it being a stable condition, only 56 (25%) had made any adaptations for LEP, see Table 33, right.

Table 33 – Type of Living Accomodation

Type of living accommodation	Total No.
Private - not adapted	143
Private – adapted	58
Rented - Council/Corporation	13
Rented - Housing Association/Social	5
Full-time residential	2
Privately Renting	1

Although not clearly stated or explored in any part of the survey dealing with the respondents housing needs, problems in this area can be foreseen when looked in conjunction with the progression of LEP that is reported elsewhere.

As can be seen from Table 33, **143 (64%) are living in non-adapted housing stock, which, in some cases, may be non-adaptable as well**. In Table 35c, Management Rating % - Mobilising indoors, 113 (50%) respondents state that they are experiencing mild difficulty now compared to 69 (31%) 5 years ago. This can only increase because of the natural ageing process being compounded by the inevitable progression of LEP on a downward spiral.

Therefore, it can be forecast that many of those respondents may well in the future wish to avail themselves of Disabled Person's Housing Grants. The OT's reported, from conversations with respondents, the great diversity in the way that these Grants are granted and administered, both in application and interpretation. It is imperative that a scheme which purports to be national, although handled on behalf of Central Government by County and City Councils, is seen to be fair and equitable and without regional or political variation.

Additional Information

The process of conducting the survey involved detailed, and sometimes personal discussions by the Occuational Therapist with each respondent. This engagement was sometimes lengthy – up to four hours, in some cases. Woven into the conversations were threads of a bigger picture of the respondents' lives, much of this being extremely valuable as it put the respondent's circumstances into context.

The key issues reported by the OT's, in order, were:

1. **Access to Services and Lack of Information about Services**
2. **Eligibility and Entitlements for Services**
3. **Social Isolation**
4. **Financial Issues**
5. **Lack of Preventative Measures**

Other issues raised and discussed included:

6. **Polio History**
7. **Work and Access**
8. **Nursing Home Residents**
9. **Travelling Community**

1. ACCESS TO SERVICES & LACK OF INFORMATION ON SERVICES

It was found that only a minority of respondents knew how and where to seek for information.

As a group, the respondents felt that, in all cases, focus should be on ability, rather than disability. It was felt that existing services are often not flexible in coping with people who have a minor disability or issue and they cannot receive assistance until their problem becomes acute.

Accessing services also means dealing with the psychological side of making services and facilities accessible, e.g. accommodating people who may be embarrassed or upset at now having to use facilities. Generally, it was felt that service providers did not give enough consideration to issues surrounding dignity and pride.

The largest number of comments and requests for assistance and help concerned the lack of information regarding:

- Existence of various services
- How to access those services
- Solving basic household problems

Specific issues that kept re-occurring were:

- Availability of orthotics, orthopaedic footwear and specialist clothing, e.g. Vasotherm stockings
- Availability of Physiotherapy, Massage Therapy, Home Help, Personal Assistants
- Availability of Community Occupational Therapists, Dieticians, Chiropody, Homeopathy, Alternative Therapies
- Availability and complexity of Disabled Person's Grant (it was noted by many that criteria vary from county to county)
- Availability of Social Worker service to provide definitive information on entitlements
- Lack of information on transport options and availability of tax relief for car adaptations and car
- Why the Disabled Driver's/Passengers Badge can not be used for toll bridge/road exemption as is the practice in some other EU countries?
- Drugs refund scheme
- Different self-help/health promotion tools available
- General safety issues, e.g. availability of panic buttons
- Education of services providers on the needs of LEP clients
- Lack of training in the use of aids and appliances
- Help in solving simple problems, such as, ability to change length of time the telephone rings
- List of clinics/services throughout the country

2. ELIGIBILITY AND ENTITLEMENTS FOR SERVICES

Respondents reported that, due to the difficulty of financing aids and appliances, many do without equipment that is needed either for medical and/or social reasons. In consequence, they are unable to adopt a preventative/proactive approach to their condition.

It was felt services are inadequate, even where they exist. For example, there is little follow-up and no training on how to use aids and appliances. This means that aids and appliances are often left unused, as they are either found to be unsuitable or the person lacks the knowledge of how to use them.

Medical professionals are not proactive/practical in their approach to solving problems for LEP patients, e.g. referrals to Neurologists who monitor, rather than rehabilitation specialists who can offer solutions.

3. SOCIAL ISOLATION

It may be argued that this area is one of the most important in the report, although completely subjective in content. It is the one area that is not quantifiable, as all the findings that are shown below were collected as comments from the survey respondents by the Occupational Therapists in the course of the interview stage of the process. In preparing the report, all the comments and recorded detail have been correlated and, in some cases, aspects deleted that could potentially identify the survey respondents.

It was found that social contact is now an increasing issue due to ageing of the LEP population. Prior to the onset of LEP, most respondents stated that they had enjoyed a full life. Now they find that the combination of age and LEP are quite restrictive. Many if not most of the survey respondents feel socially isolated. Possible factors include:

a. Country vs. city living
b. Level of disability
c. Working or not working
d If they have relatives living with them
e. Mental Health issues
f. Transport – suitable with assistance
g. Finance (mostly for transport)
h. Lack of information about how to get assistance for social contact
i. Lack of confidence

Respondents often stated the need to get away from their families and have a break, and to give their families a break from the caring role.

Respondents said they were unaware of others in the same situation and felt that some form of peer support would beneficial.

It was noted that, as mobility decreases, social contact decreases. Transport is a key issue and this is directly related to financial issues around socialisation in general.

Respondents still able to drive had an issue with respect to the type of wheelchair used, as well as getting it in and out of the car. A further issue was the manual versus powered wheelchair argument as well as the affordability of new vehicles together with the applicable criteria under Revenue Commissioner Regulations (Vehicles for People with Disabilities – Tax Relief Scheme, VRT 7, March 2002).

Many people do not see a way out of the social isolation issue. This, it was noted, was compounded if the respondent did not have a personal assistant or carer to assist them when out, i.e. not confident enough (mobility wise) to access public buildings and general environment without assistance.

It was felt that respondents in country areas enjoyed more support from neighbours and in general have more community support and assistance. This was not found to be true in the city and urban environments.

Those who have no close relatives are often anxious and have more and more difficulty getting out, as they grow older.

4. FINANCIAL ISSUES

There was general concern amongst respondents that, in seeking further financial advice from State or semi-state bodies, they would endanger any benefits and entitlements they already enjoyed.

Transport was found to be expensive and there was general concern about the cost of purchasing a suitable vehicle, even amongst those in receipt of tax relief on fuel and car purchase.

Respondents were concerned and need information about preparing for retirement.

Respondents over retirement age, who are in receipt of pensions, found that the amount does not meet their needs, which are increased due to their disability, i.e. fuel, transport, assistance, etc. Respondents also noted that providers, due to their circumstances, treated them as second class citizens.

5. LACK OF PREVENTATIVE MEASURES.

Respondents reported a lack of knowledge surrounding Poliomyelitis and LEP by medical professionals in general. This means they are neither able nor properly equipped to provide appropriate advice.

It was noted by the Occupational Therapists that many of the respondents were either in the early stages of acceptance or in denial of LEP meaning that they are either unwilling or unable to engage in prevention of their symptoms.

It was further noted by the OT's that there was a lack of awareness by respondents of the need to have their symptoms assessed and, also, of the need to conserve energy.

It was found that compensatory techniques adopted by respondents lead to subsequent additional problems for two reasons:

- Lack of acceptance of their condition before they are forced to
- Lack of suitable services to provide preventative measures when required

6. POLIO HISTORY

The OT's found, in the main, that respondents wanted to talk about their original Poliomyelitis history, how it was managed and what worked best.

It was noted that active physiotherapy and gentle massage worked well, as opposed to those who had full body casts and were kept still. Respondents felt that this information may be of use to foreign countries still dealing with active Poliomyelitis.

In a few cases (less than 5), it was reported that infection was as a direct result of the vaccine.

Respondents reported that siblings who were healthy all their lives are now demonstrating symptoms of LEP.

7. ACCESS TO WORK AND WORKPLACES AND LEGAL REDRESS

Some respondents gave verbal evidence that LEP was not being recognised by employers and that their statutory rights under employment laws were being infringed.

In many cases, it would appear that neither respondents nor employers are aware of the grants that are available for the adaptation of the workplace.

Many respondents reported that they are unable to undertake a full week's work due to fatigue.

8. NURSING HOME RESIDENTS

Due to the status of LEP under social and medical welfare legislation, residents of Nursing Homes enjoyed very few entitlements.

Some of the more elderly respondents were anxious to know how to get placements and information in general about moving to a Nursing Home

9. TRAVELLING COMMUNITY

It should be noted that there were no members of the Travelling Community amongst the respondents. However, it would be fair to assume that they would experience the same problems as members of the community at large, as well as further difficulties associated with their increased marginalisation.

Progression of LEP Condition

The only fact that holds true for all the respondents to the survey is that LEP is progressive and will get worse. However, how the respondents see and deal with the situation can be very different. Just as how they coped with the original bout of paralytic Polio seems to have influenced how well they managed their lives to date, so those same coping mechanisms will dictate how they will manage with LEP in its progressive form. It should also be remembered that all those with LEP are also subject to the normal ageing process and that the opinions and assessments made on the respondents are in addition to those factors that affect the population in general.

Table 34 – How do you View the Future?

How do you view the future?	Perceived status in the next 5 years No.	Perceived status in the next 5 years %
Will try to stay independent	186	83
See condition worsening slowly	134	60
Will manage with additional aids	116	52
Will manage current situation	110	49
Will accept potential change	98	44
Will need house adaptation	87	39
Concerned about condition worsening	78	35
Will need assistance	77	34
Do not foresee major changes	74	33
Will need further assistance	71	32
Unsure how to manage if LEP gets worse	39	17
Will need a lot more help	20	9
See condition worsening quickly	13	6
Will deal with situations as they arise	9	4
Family support is vital	7	3
Will need residential care	6	3
Do not want to think about future	5	2
Concern at loss of independence	5	2
Will seek assistance as necessary	5	2
Would like to stay independent	4	2
Do not think I have PPS	3	1
Other & Not stated	2	7

Note: These were multiple choice answers so respondents were able to voice all views.

However, the whole picture does not become clear until the detail is examined on daily tasks and how respondents viewed their abilities now, 12 months and 5 years ago. The story this tells shows the decline in daily living that can occur for those with LEP. Tables 35a – d below are merely examples extracted from the total data that can be found in Appendix B.

Table 35a - Management Rating % - Ambulant

	At Present %	12 Months Ago %	5 Years Ago %
Extreme	1	1	2
Severe	0	0	0
Moderate	16	11	4
Mild	51	52	31
None	25	28	56
Does not apply	3	3	2
Not stated	4	4	4

Table 35b - Management rating % - Walking without sitting to rest

	At Present %	12 Months Ago %	5 Years Ago %
Extreme	2	2	1
Severe	4	4	1
Moderate	27	17	9
Mild	42	47	28
None	14	19	51
Does not apply	5	5	5
Not stated	5	4	4

Table 35c - Management rating % - Mobilising indoors

	At Present %	12 Months Ago %	5 Years Ago %
Extreme	0	0	0
Severe	0	0	0
Moderate	8	7	5
Mild	50	48	31
None	39	41	61
Does not apply	0	0	0
Not stated	2	3	2

Table 35d - Management rating % - Mobilising outdoors

	At Present %	12 Months Ago %	5 Years Ago %
Extreme	0	0	0
Severe	4	4	1
Moderate	16	13	6
Mild	55	54	41
None	24	28	50
Does not apply	0	0	0
Not stated	1	1	1

Note: Definitions:

Extreme - Cannot manage at all
Severe - Cannot manage alone
Moderate - Can manage – someone helping/struggling on their own
Mild - Can manage with assistive aids or appliances/altered approach
None - Can manage alone

In all cases, a slow but inexorable decline can be seen. Although when looked upon over the last 12 months it does not seem dramatic, the true picture can only be envisaged when comparing the present to 5 years ago. The decline may not seem that much to the casual observer but, to those with LEP, it feels as if they have been deprived of their lives and fulfilment. To a person who has been able to get out and about without difficulty for over 30 years, now to have to plan every move, as well as ask for assistance, is a major and defining life style change. This can cause both sociological and psychological problems through feelings of isolation, ineptitude and lack of worth (Creange & Bruno, 1994).

When the respondents looked at the criticality of functional daily tasks, it reinforced the problems caused by the progressive decline demonstrated above. Table 36 below is again an example, with the main data to be found in Appendix C:

Table 36 - Criticality Rating %

	Ambulant %	Mobilising indoors %	Mobilising outdoors %
Critical to daily routine	88	84	61
Usual to daily routine	3	14	25
Occasional Task only	1	1	11
Not part of any routine	5	0	0
Does not apply	0	0	0
Not stated	3	0	2

Due to the difficulties that had been identified by the respondents in their daily lives, 142 (63%) respondents at the time of the survey had already sought assistance covering a multitude of areas from transport to obtaining a ramped household entrance. Table 37 below shows the most common requests:

Table 37 – Assistance Requested by Type

Assistance Sought	No.
Aids & appliances	84
Medication for pain relief	59
Physiotherapy	55
Assistance with mobility	49
Private transport	36
Applied for Medical Cert.	26
Application for Disabled Housing Grant	15
Alternative therapy	7
Personal assistant	5
Massage	4
Public transport	4
Orthotics/shoes/callipers	4
Medical Card	3
Having bath and/or stairs adapted	3
Reclining chair	3
Massage chair	2
Back support for car	2
Heating allowance	1
Driving	1
Outside ramp	1
Trolley	1

Of those who had not sought assistance, 76 (34%) gave reasons and these ranged from not needing help, not having thought about it, to cost. Interestingly, given the responses that were reported in the Additional Information section, where frustration about lack of information and sources of help were reported, only 6 respondents in this section said they were unable to locate assistance or had become too frustrated in the process to carry the matter further.

Table 38a - Allocation of funds by PPSG to aids, appliances, orthotics and adaptations

	€ '000
Appliances	53.0
Orthotics	1.8
Aids to Daily Living	3.0
Building Adaptations	3.5
TOTAL	61.4

Table 38b - Allocation of funds by PPSG to services

	€ '000
Physiotherapy	2.0
Respite Break	4.0
Counselling	1.0
TOTAL	7.0

However, figures from the PPSG itself show that many, whilst not making a direct approach to statutory agencies and bodies, appear to feel less inhibited when applying to their own Support Group. The figures for the period 2002-2003 show that the PPSG has supplied aids, appliances, equipment and services to assist the daily living needs of its members, with money raised, almost exclusively, through fundraising and voluntary donations.

As well as allocating funds directly generated through fundraising, PPSG has administered and distributed grants, which it received from various Health Boards, to Polio Survivors for Aids and Appliances and Services. These grants have been administered at no cost to the Health Boards and have enabled PPSG to provide direct assistance to Polio Survivors.

For Aids and Appliances, PPSG received and distributed approximately IR£14,000 in 1998 - 1999, IR£14,000 in 1999 - 2000, IR£10,000 in 2000 - 2001 and €35,000 in 2001 - 2002. In addition, PPSG has successfully sought and distributed Health Board grants for development services such as Physiotherapy, Counselling and Respite Breaks.

PPSG

Present & Future Needs

The respondents were assessed as to their needs both now and in the future. The list that was compiled is exhaustive and covers items such as wheelchairs to simple items required to assist daily living functions. Some of those who responded said they needed multiple items, and Table 39 below shows those needs at the time of the survey, and then 2 and 5 years down the line.

Table 39 – Self-Assessed Needs to Mobility & Daily Living

	Current Needs Units	Additional at 2 years Units	Additional at 5 Years Units
Bathroom Equipment			
Shower Chair	24	20	11
Shower Seat	18	14	6
Toilet Raiser	14	7	13
Toilet Frame	7	8	6
Bath Seat	18	16	7
Walk-In Shower	32	25	25
Powered Bath Lift	20	11	4
Bed Room			
Mattress Variator	3	2	3
Bed Raisers	2	1	1
Bed Rest	1	1	2
Bed	3	10	14
Respirator	3	1	1
Mobility Aids			
Wheelchair Powered	2	11	34
Wheelchair Manual	6	15	23
Wheelchair Transit	1	0	6
Wheelchair Cushion	7	10	9
Gel Cushion	4	4	4
Non Puncture Tyres Power Chair	0	1	6
Portable Ramp	2	7	2
Shopping Scooter	6	10	10
Walker	2	2	2
Tripod	4	3	6
Calliper (each)	17	33	20
Spine Brace	2	2	1
Other Brace	2	5	2
Stair Lift	8	10	16
Car Hoist	0	5	2

Table 39 – Self-Assessed Needs in Mobility & Daily Living (cont.)

	Current Needs Units	Additional at 2 years Units	Additional at 5 Years Units
Mobility Aids cont.			
Special Shoes	25	34	14
Orthotics For Shoes	22	26	10
Transfer Aid	3	2	1
Kitchen Living Area			
Special Chair	12	14	14
Perching Stool	29	22	10
Trolley	18	8	6
Office Chair	6	2	2
Aids to Daily Living			
Dust Pan	18	2	2
Mat Non slip	15	2	1
Cutlery	2	2	1
Kettle tilter	6	5	1
Grab Rail	58	33	18
Crutches	2	12	11
Garden Tools	13	7	2
Hand Reacher	30	11	11
Tights Aid	8	3	0
Orthopaedic Pillow	6	0	0
Personal Alarm	9	3	6
Pneumatic Bath Lift	2	3	0
Long Handled Shoe Horn	20	10	3
Transfer Board	2	4	1
Adjustable Kitchen Stool	5	5	3
Kneeler	8	1	1
Total for Years	**527**	**445**	**354**

It can be seen from Table 39 that the one area where there is great concentration of need is Bathroom Equipment and this correlates with the responses to questions about the progression of LEP, where toileting and dressing/undressing scored highly on the criticality tables (Appendix C).

Further areas which show great need are orthotics and mobility aids. Equipment of this type is expensive and, although needed desperately, is all too often not purchased due to the high prices, i.e. callipers at €1000 minimum per leg and power chairs in the region of €4000 upwards, dependent upon specification.

These needs which, when met, will often slow down the rate of deterioration, would be met in full if the person with a clinical diagnosis of LEP was granted a medical card, in the first instance in their own right.

As a further part of the interview process, the Occupational Therapists were asked to assess whether the respondents were in need of any other type of equipment. Interestingly, the extra needs noted were few.

Table 40a – OT assessed extra equipment needs

	Units
Office Equipment	1
Button Hook	2
Walking Stick	7
Stair Rail	3
Foot Rest	1
Bath Spa	1
Bed Lever Board	3
One-hand Kitchen Equipment	1
Chair Leg Raisers	1
Walking Stick Ferrule	1
Accessible Toilet	1
Arm Support	1
Power Assisted Wheels	1
Bathroom Heater	2
Car Seat Support	1
Lower Light Switches	1
Feeding/Cooking Aids	1
Rollabar	1
Safer Step	1
Non Slip Tiles	1

In addition to looking at equipment needs, the OT's were asked to assess the additional service needs of the respondents.

Table 40b – OT assessed extra service needs

	Immediate Need %
Physiotherapy	30
Occupational Therapy	25
Complementary Therapy	18
Neurology	18
Orthotist/Prosthetics	17
PPSG support	16
Chiropody	15

Another service covered was Respite Care. Some 166 (75%) of respondents felt that they were not in need, whilst another 26 (12%) have availed of it in the past with a further 27 (12%) believing they are in need of it, but are unable to access the service. The OT's recommended a higher level of Respite Care for the future, 67 (30%), over the next 12 months with 47 (21%) on an ongoing basis. The OT's also made the judgement that 13 (16%) of carers need a break in the next year with 7 (9%) availing of such an arrangement on an ongoing basis. The need for the breaks can be plainly seen when looking at the level of care that is given on a daily unpaid basis (see Tables 31a & 31b).

Note: Due to the very individual requirements of the above needs it has not been possible to make an estimate of the total revenue that would be involved.

THE COSTS

It was necessary, in order to quantify the overall costs of meeting these needs, to conduct some market research into the pricing of products for people with disabilities. This in itself, whilst not strictly part of the survey, has thrown up some extremely worrying trends in the way that products are priced in the Irish market compared to, say, the UK and nearby EU neighbours. For example, a shower chair demonstrates an average price in Ireland of €550 compared to a retail of just under €200 (£140) in the UK (£1 = €0.70). Boxes that hoist and carry wheelchairs on the roofs of cars retail fully fitted in Ireland at €6,500 – €7,200 whist in the UK the price is €3,800 - €4,550 (£2,645 - £3,195). The differential affects virtually all types of equipment and aids to daily living and requires investigation by regulatory authorities.

Taking all the needs of the 224 respondents to the survey it was possible to draw up the financial implications and these are shown in table 41 below:

Table 41 – Table of costs for self assessed needs to mobility and daily living

	Current Needs € '000	Additional at 2 years € '000	Additional at 5 Years € '000
Bathroom Equipment			
Shower Chair	13.2	11.0	6.1
Shower Seat	2.8	2.2	1.0
Toilet Raiser	0.5	0.3	0.5
Toilet Frame	1.0	1.2	0.9
Bath Seat	0.8	0.7	0.3
Walk-In Shower	112.0	87.5	87.5
Powered Bath Lift	15.3	8.4	3.1
Bed Room			
Mattress Variator	2.9	1.9	2.9
Bed Raisers	0.1	0.1	0.1
Bed Rest	0.1	0.1	0.1
Special Bed	8.5	28.4	39.8
Respirator	18.0	6.0	6.0
Mobility Aids			
Wheelchair Powered	6.5	35.8	110.6
Wheelchair Manual	3.9	9.7	14.7
Wheelchair Transit	0.4	0.0	2.4
Wheelchair Cushion	1.1	1.5	1.4
Gel Cushion	2.0	2.0	2.0
Non Puncture Tyres Power Chair	0.0	3.5	21.2
Portable Ramp	1.0	3.3	1.0
Shopping Scooter	21.0	35.0	35.0
Walker	0.3	0.3	0.3

Table 41 – Table of costs for self assessed needs to mobility and daily living (cont.)

	Current Needs € '000	Additional at 2 years € '000	Additional at 5 Years € '000
Mobility Aids			
Tripod	0.3	0.2	0.5
Calliper (EACH)	17.0	33.0	20.0
Spine Brace	0.1	0.1	0.1
Other Brace	0.1	0.2	0.1
Stair Lift	48.0	60.0	96.0
Car Hoist	0.00	7.5	3.0
Special Shoes	10.0	13.6	5.6
Orthotics For Shoes	0.9	1.0	0.4
Transfer Aid	0.2	0.1	0.1
Kitchen Living Area			
Special Chair	22.4	26.1	26.1
Perching Stool	3.1	2.4	1.1
Trolley	3.1	1.4	1.0
Office Chair	1.9	0.6	0.6
Aids to Daily Living			
Dust Pan	0.4	0.1	0.1
Mat Non slip	0.2	0.1	0.0
Cutlery	0.2	0.2	0.1
Kettle tilter	0.1	0.1	0.1
Grab Rail	0.7	0.4	0.2
Crutches	0.7	0.5	0.5
Garden Tools	1.3	0.7	0.2
Hand Reacher	1.4	0.5	0.5
Tights Aid	0.1	0.1	0.00
Orthopaedic Pillow	0.2	0.0	0.00
Personal Alarm	3.1	1.0	2.1
Pneumatic Bath Lift	2.1	3.2	0.00
Long Handled Shoe Horn	0.4	0.2	0.1
Transfer Board	0.1	0.2	0.1
Adjustable Kitchen Stool	0.7	0.7	0.4
Kneeler	0.1	0.1	0.1
Total for Years	**329.4**	**392.8**	**495.2**

The survey shows that to meet all the needs of the respondents over the next 5 years the total cost based on current Irish retail prices will be just under €1.25 million (see Table 42, below).

This equates to an average cost per respondent of some €5,450. The PPSG had a membership at time of writing (August 2003) of some 450, so it can, therefore, be deduced that to satisfy all their needs for mobility and aids to daily living the members need some €2.4m at 2003 prices.

Extrapolated across the whole of the derived LEP population in Ireland (see Introduction), this amounts to some €23m being needed across the next 5 years to satisfy the perceived needs of those with LEP. What cannot be stated until after the event is what it will cost if nothing is done. As has been shown (Young, 1992), intervention at an early stage, and with preventative methods, can and does slow down the rate of deterioration.

Table 42 – Summary of 5 Year Financial Implications at 2003 Prices

	Summary of 5 Year Cost € '000
Cost per Survey Respondent	5.5
Cost of Respondent Group (224)	1,250.0
Cost of PPSG Membership (450)	2,400.0
Cost of potential Irish LEP Population (3,000)	23,000.0

It should be noted, however, that the true cost that would accrue to the State would be offset by the amount that carers donate to the coffers through their unpaid services, i.e. some €12.65m per annum. It can, therefore, be argued that through these hidden contributions to the State, even if all aids and appliances were funded by central Government, then the State would still be some €40m better off.

Note: The costs shown above are purely for aids and appliances and do not take into account any extra costs that may be incurred through the granting, or extension in scope, of any State benefits, grants and entitlements. It should be further noted that, due to constraints in data analysis, it was not possible to extract the needs of those already in receipt of medical cards, i.e. over 70 years old, nor to estimate the repeat rate of consumables such as shoes, callipers, wheelchairs, etc.

SUMMARY OF FINDINGS

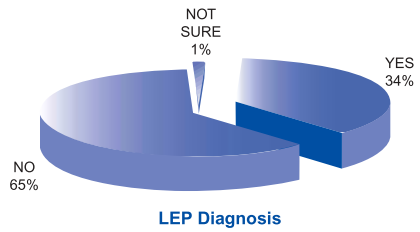
The main findings of the survey are:

1. Reduction in Physical mobility

Overall, most respondents have experienced some reduction in physical ability over the last five years in a range of areas, mostly around mobility. The pace of this change does appear to be relatively slow with most of the change occurring in from None to Mild, some change from Mild to Moderate and a very small amount of change from Moderate to Severe.

People are finding most difficulty with walking (without sitting to rest), bathing, getting out of their homes, shopping and accessing the community. Bathing and mobility are the two most pressing issues with respect to physical assistance - aids, appliances and services.

2. Population diagnosed with the Late Effects of Polio



There are 74 (34%) respondents with a clinical diagnosis. Most (48 (68%)) were diagnosed by Dr. Orla Hardiman at the Beaumont Clinic in Dublin but there was also a wide variety of other medical practitioners who made diagnoses. The earliest diagnosis of LEP reportedly recorded in Ireland was in 1960, with the majority starting around 1990, with the bulk being in the last five years.

3. Links between mobility & access to the built environment with Transport, Employment and Social Isolation.

It was established beyond all reasonable doubt that there is a definite link between decreased mobility and social isolation. This is not helped by the dearth of adapted or suitable public transport outside of Dublin and other cities, i.e. low floor buses. Benefits relating to mobility need to be made available regardless of age. As one respondent said "Why don't they pay mobility allowance to people over 65? Free travel isn't much good to folk in a wheelchair, particularly in the country".

Issues that need addressing include:

- Information on reduced mobility
- Reduced access to the external built environment
- Issues raised around employment
- Social isolation and the potential for mental health problems. (Information on respondents' mental health was not gathered in the survey.)

4. Underlying financial issues

- Many respondents, 84 (38%), are living with their children, many of these still dependent.
- 63 (31%) respondents appear to be living at or below the equivalent of the statutory minimum wage level of €6.35 per hour (experienced Adult worker – August 2003), irrespective of what their ages are.
- Respondents in general feel the need for information about preparing for retirement. Many are concerned about seeking financial advice in case they lose some of their existing entitlements.
- People under 65 on State benefits and those on pensions are finding these do not meet their needs. The amount is too low and they find they are treated like second-class citizens, i.e. the attitude from those dealing with them is poor.
- Cost for individuals buying aids and appliances can be high when wear and tear and the need for upgrading is taken into account.
- The costs of aids and appliances is some 30 – 50% higher in Ireland than UK or other neighbouring EU countries (Marketing Matters, October 2002).

5. Lack of a planned approach – services and information are uncoordinated and ad-hoc.

There are a number of key aspects to this issue:

- Respondents AND health workers knowing what services are available and possible.
- Respondents AND health workers knowing what entitlements are available and how they are determined.
- Lack of effectiveness of treatments offered when they are unlinked, uncoordinated and not followed-up.

These are all aspects - equitable access, eligibility, access and poor integration of services within the system - already highlighted as weaknesses in the Health System in the Government 2001 Health Strategy (p. 47 - 48).

It would appear that, in many cases, those who should be able to advise are either ill equipped to do so or not properly trained. Few of the respondents knew, on their own volition, where to gain information. It was felt by many that information regarding benefits, allowances and entitlements is treated like a state secret, rather than being easily accessible in the public domain by right.

It was found that making services user friendly also means dealing with the psychological side of making services and facilities accessible, e.g. accommodating those who may be embarrassed or upset at now having to use facilities. Consideration of issues surrounding dignity and pride must be taken into consideration. This issue relates to the Health System being geared around acute and emergency situations and, also, that respondents perceive that the need to use such systems signals their own decay, which can be distressing.

6. The Government's view on Poliomyelitis and LEP

Currently, neither Poliomyelitis nor LEP are viewed by the statutory authorities as a long-term neurological illness. This view can and has been proved to be false both in fact and substance and respondents now are demanding that they be treated in the same way as others with debilitating neurological diseases, i.e. Multiple Sclerosis, Muscular Dystrophy.

Furthermore, as may be determined from some of the verbal evidence gathered during the compilation of this report, there is a need for consistency in the application of regulations concerning the allocation of services, i.e. Medical Cards, Disabled Persons' Housing Grant, etc.

It would further appear that respondents who may have to enter Nursing Homes do not have entitlements – although this view does not take into account possible subvention.

There is a need for standardised objective criteria across the system when allocating services, i.e. Medical Cards, Disabled Persons' Housing Grant, Primary Medical Certificate, etc.

7. Lack of Service Co-ordination

Many respondents reported that they were in receipt of a number of services, e.g. physiotherapy, neurological assessment, occupational therapy, but that these were often not followed up at a later date or connected together in a cohesive manner that would form a case plan. This leads to a lack of knowledge amongst the providers - GP's, therapists, neurologists, service providers, etc. - of the total needs of the service user.

There are also implications here for cost, as many treatments are started and not continued. For example, there is little follow-up or training on how to use aids and appliances. This means that many aids and appliances are left unused as they are either not suitable or the person does not know how or have the confidence to use them.

In turn, it was found that there is a great lack of awareness among the respondents concerning the assessment of symptoms and the need to conserve energy, so as to maintain longer lasting quality of life (Young, 1994). Much can be done to alleviate and manage symptoms as well as to assist the maintenance of an independent lifestyle. Studies (Peach & Olejnik, 1991) show that proper management of symptoms has a significant effect on the rate of slowing deterioration compared with those who do not manage their symptoms.

8. Emergency mentality vs. supporting wellness

The Irish Health System is geared to "sick" people – those who have acute symptoms and are ill. Often, existing services are not flexible in coping with people who have a minor disability or issue; they are unable to receive assistance until their problem is acute.

For those with a mild disability or wanting to seek assistance from the system, it appears that people need to be classified as "sick" or "poor" or both before being eligible for assistance. People who have a disability may need assistance from time to time but do not see themselves as being "sick".

An additional factor is that many of the respondents are in the early stages of acceptance of LEP and are or may be reluctant to engage in prevention of their symptoms (Bruno & Frick, 1991). Encouragement and incentives by the service providers are needed, so that there is an early take up of preventive measures, i.e. aids and appliances, taking regular rest breaks, diet, exercise and possibly alternative therapies.

Creange and Bruno (1995) have also showed that "the proactive management of LEP by the individual has been shown to be greatly enhanced by support from understanding family and friends".

It was found that many of the respondents have difficulty in adopting a preventative/proactive approach to their condition as they do not have finances to buy aids and appliances. Evidence of this may be seen in the annual allocation of funds that PPSG allocate to aids, appliances, respite, and therapies (see Tables 38a & 38b). This often means that many people have to do without. This can be either through lack of knowing that aids and appliances can/will help, or because they do not have the finances to buy their own equipment.

9. The Cost

The average cost per respondent over the next 5 years of meeting all the needs for aids and appliances equates to some €5,450 at 2003 prices. The PPSG has a membership at time of writing (August 2003) of 450, so it can, therefore, be deduced that, to satisfy all their needs for mobility and aids to daily living, the members need some €2.4m at 2003 prices.

Extrapolated across the whole of the derived LEP population in Ireland (see Introduction), this amounts to around €23m being needed across the next 5 years to satisfy the perceived needs of those with LEP. As previously mentioned (see Table 42), it should be noted, however, that the true cost that would accrue to the State would be offset by the amount that carers donate to the coffers through their unpaid services, i.e. €12.65m per annum. It can, therefore, be argued that, through these hidden contributions to the State, even if all aids and appliances were funded by central Government, the State would still be some €40m better off.

However, the cost to the State may well be reduced if the regulatory authorities can determine why there is such a high price differential between prices prevailing in the jurisdiction and those in the UK and other neighbouring EU states. This differential may explain why some UK dealers are reporting a cross-channel trade for the higher priced items, such as wheelchair hoists and particular car adaptations.

10. General

The survey and its conclusion paint a picture of a portion of Irish society that will almost entirely disappear within the next 35 years. Demographic and morbidity trends show that the main bulk of those who were affected by paralytic Poliomyelitis and/or LEP will have died by 2030.

However, the overwhelming impression that is gained from both the analysis of data as well as the verbal evidence is one of isolation, as well as being fearful of the progression of LEP and of the State's attitude toward their plight.

APPENDIX A - Additional Costs by Income Group

Respondents reporting additional costs by income level (€ per month)

Income Group	Personal Transport No.	Public Transport No.	Telephone No.	Heat & Light No.	Clothing No.	Footwear No.	Number in Income Group No.
Less than €509	8	3	8	13	12	10	19
€509-€1016	31	13	30	34	27	30	46
€1017-€1524	35	14	35	40	32	34	46
€1525-€2031	24	8	25	29	22	24	32
€2032-€2539	14	6	13	15	12	12	19
€2540-€3047	13	5	13	15	11	14	21
€3048-€3555	5	1	5	5	5	4	5
€3556-€4063	4	0	2	3	2	4	6
More than €4063	3	3	3	3	6	5	13
Not sure	4	2	5	5	3	5	7
Total	141	55	139	162	132	142	214

Note: *Only 214 of 224 respondents completed both these sections.*

APPENDIX B - Management Rating % by task – Now, 1 Year & 5 Years Ago

Management Rating % by task – Now

Management Rating Now	Extreme %	Severe %	Moderate %	Mild %	None %	Doesn't apply %	Not stated %
Ambulant	1	0	16	51	25	3	4
Walking without sitting to rest	2	4	27	42	15	5	5
Climbing stairs	2	4	21	43	11	11	7
Mobilising inside the house	0	0	8	50	40	0	2
Getting into and out of house	0	1	9	54	34	0	0
Mobilising outside	0	4	16	55	25	0	1
Dressing/undressing	2	1	8	35	52	0	0
Washing	0	1	6	22	67	1	1
Taking a bath/shower	3	4	14	52	25	0	2
Toileting	0	2	7	35	54	0	1
Grooming/shaving	0	1	6	20	69	0	3

APPENDIX B (cont.) - Management Rating % by task – Now, 1 Year & 5 Years Ago

Management Rating % by task – Now

Management Rating Now	Extreme %	Severe %	Moderate %	Mild %	None %	Doesn't apply %	Not stated %
Meal preparation - cooking	1	3	10	42	34	7	2
Eating & drinking	0	0	3	12	83	0	0
Washing dishes	0	2	4	30	53	7	3
Household cleaning	2	9	19	31	17	16	4
Laundry	1	6	9	32	29	18	4
Setting a fire	3	5	11	13	14	38	16
Goes out as required	0	4	15	44	33	1	2
Able to mobilise when going out	0	5	19	49	25	0	1
Can carry out leisure activities	3	5	13	44	26	7	1
Step up a kerb or obstacle	3	4	21	45	19	3	4
Get in and out of car/transport	1	4	17	45	31	1	2
Driving	1	1	3	44	31	16	4
Loading and unloading car	5	10	17	29	14	20	4
Able to use community facilities	2	7	8	36	36	9	2
Shopping	1	6	25	39	17	9	2
Performing tasks in paid work	1	0	5	22	16	30	25

Note: *Definitions:*

Extreme - Cannot manage at all
Severe - Cannot manage alone
Moderate - Can manage with someone helping or by struggling on their own
Mild - Can manage with assistive aids or appliances/altered approach
None - Can manage alone

Appendix B (cont.)

Management Rating % by task – 1 Year Ago

Management Rating 1 Year ago	Extreme %	Severe %	Moderate %	Mild %	None %	Doesn't apply %	Not stated %
Ambulant	1	0	11	52	28	3	4
Walking without sitting to rest	2	4	18	46	20	5	4
Climbing stairs	2	5	15	46	13	11	7
Mobilising inside the house	0	0	7	47	42	0	3
Getting in & out of house	0	2	9	51	37	0	0
Mobilising outside	0	4	13	54	28	0	1
Dressing/undressing	2	1	8	32	57	0	0
Washing	0	1	6	21	70	1	1
Taking a bath/shower	3	3	12	49	31	0	2
Toileting	0	2	6	32	58	0	1
Grooming/shaving	1	1	5	20	69	0	3
Meal preparation - cooking	1	3	8	40	38	7	2
Eating & drinking	0	0	3	11	85	0	0
Washing dishes	0	2	4	28	54	6	4
Household cleaning	2	7	19	30	21	16	4
Laundry	1	5	10	30	31	17	4
Setting a fire	2	4	11	13	16	38	16
Goes out as required	0	3	11	45	37	1	2
Able to mobilise when going out	0	5	14	50	29	0	1
Can carry out leisure activities	3	4	13	42	29	7	1
Step up a kerb or obstacle	3	5	15	46	23	3	4
Get in and out of car/transport	1	4	12	45	34	1	2
Driving	1	1	1	43	33	15	5
Loading and unloading car	4	8	17	30	16	19	5
Able to use community facilities	2	6	7	35	38	9	2
Shopping	2	6	22	38	21	8	2
Performing tasks in paid work	0	0	5	22	17	30	24

Note: *Definitions:*

Extreme - Cannot manage at all
Severe - Cannot manage alone
Moderate - Can manage with someone helping or by struggling on their own
Mild - Can manage with assistive aids or appliances/altered approach
None - Can manage alone

Appendix B (cont.)

Management Rating % by task – 5 Years Ago

Management Rating 5 Years ago	Extreme %	Severe %	Moderate %	Mild %	None %	Doesn't apply %	Not stated %
Ambulant	2	0	4	31	56	2	4
Walking without sitting to rest	1	1	9	28	51	5	4
Climbing stairs	0	2	8	35	38	11	5
Mobilising inside the house	0	0	5	31	61	0	2
Getting in & out of house	0	0	5	34	59	0	0
Mobilising outside	0	1	6	40	51	0	1
Dressing/undressing	1	1	4	21	71	0	0
Washing	0	2	2	14	79	1	1
Taking a bath/shower	2	4	7	26	58	1	2
Toileting	0	2	3	22	71	0	1
Grooming/shaving	1	2	2	17	75	0	3
Meal preparation - cooking	0	2	2	24	63	7	2
Eating & drinking	0	0	1	8	88	0	0
Washing dishes	0	2	1	20	67	6	4
Household cleaning	0	4	9	21	46	15	4
Laundry	0	5	4	20	48	17	4
Setting a fire	1	3	4	11	26	38	16
Goes out as required	0	1	5	26	63	1	2
Able to mobilise when going out	0	3	6	31	59	0	1
Can carry out leisure activities	0	3	7	25	56	7	2
Step up a kerb or obstacle	0	2	9	32	49	3	5
Get in and out of car/transport	1	1	6	31	57	1	2
Driving	1	1	0	32	46	15	5
Loading and unloading car	3	6	9	22	38	17	4
Able to use community facility	1	4	4	25	55	8	2
Shopping	1	4	11	25	49	8	2
Performing tasks in paid work	0	0	2	11	32	30	24

Note: *Definitions:*

Extreme - Cannot manage at all
Severe - Cannot manage alone
Moderate - Can manage with someone helping or by struggling on their own
Mild - Can manage with assistive aids or appliances/altered approach
None - Can manage alone

APPENDIX C - Functional Daily Tasks by criticality - %

Functional Daily Tasks	Dressing/ undressing %	Toileting %	Ambulant %	Eating & drinking %	Mobilising inside the house %	Washing %	Grooming/ shaving %	Getting into and out of house %	Taking a bath/ shower %
Critical to daily routine	94	89	88	87	84	83	78	77	63
Usual to daily routine	4	9	3	11	14	14	16	19	26
Occasional task only	0	0	1	1	1	0	1	3	6
Not part of any routine	0	0	5	0	0	0	0	0	3
Doesn't apply	0	1	0	0	0	1	1	0	1
Not stated	0	0	3	0	0	1	4	0	1

Functional Daily Tasks	Mobilising outside %	Go out as required %	Able to mobilise when goes out %	Get in and out of car/ transport %	Driving %	Meal preparation - cooking %	Washing dishes %	Climbing stairs %	Walking without sitting to rest %
Critical to daily routine	61	59	56	55	53	53	46	43	40
Usual to daily routine	25	27	30	29	20	21	30	9	33
Occasional task only	11	12	13	11	4	14	12	22	14
Not part of any routine	0	1	0	2	21	11	11	23	10
Doesn't apply	0	0	0	0	0	0	0	0	0
Not stated	2	0	0	2	2	0	1	3	3

Functional Daily Tasks	Performing tasks in paid work %	Step up a kerb or obstacle %	Can carry out leisure activities %	Household cleaning %	Laundry %	Loading and unloading car %	Able to use community facilities %	Shopping %	Setting a fire %
Critical to daily routine	34	32	24	19	19	15	13	11	10
Usual to daily routine	8	33	30	30	33	28	27	29	16
Occasional task only	4	24	32	24	21	22	43	43	11
Not part of any routine	34	8	13	23	24	31	15	13	52
Doesn't apply	0	0	0	0	0	0	0	0	0
Not stated	20	3	1	3	2	3	0	3	10

APPENDIX D - Aids & Appliances 5 Year Cumulative Needs & Costs by Health Authority/Board

Eastern Region Health Authority - East Coast Area Health Board

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	3	1.7
Shower Seat	7	1.1
Toilet Raiser	7	0.3
Toilet Frame	2	0.3
Bath Seat	6	0.3
Walk-In Shower	6	21.0
Powered Bath Lift	2	1.5
Bed Room		
Mattress Variator	0	0
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	4	11.4
Respirator	0	0
Mobility Aids		
Wheelchair Powered	3	9.8
Wheelchair Manual	5	3.2
Wheelchair Transit	0	0
Wheelchair Cushion	1	0.2
Gel Cushion	1	0.5
Non Puncture Tyres Power Chair	0	0
Portable Ramp	3	1.4
Shopping Scooter	4	14.0
Walker	0	0
Tripod	3	0.2
Calliper (each)	8	8.0
Spine Brace	0	0
Other Brace	0	0
Stair Lift	4	24.0
Car Hoist	2	3.0
Special Shoes	7	2.8
Orthotics For Shoes	4	0.2
Transfer Aid	0	0

Eastern Region Health Authority –
East Coast Area Health Board **(cont.)**

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	3	5.6
Perching Stool	5	0.5
Trolley	3	0.5
Office Chair	0	0
Aids to Daily Living		
Dust Pan	1	0
Mat Non slip	0	0
Cutlery	0	0
Kettle tilter	0	0
Grab Rail	12	0.2
Crutches	3	0.1
Garden Tools	0	0
Hand Reacher	6	0.3
Tights Aid	1	0
Orthopaedic Pillow	0	0
Personal Alarm	2	0.7
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	3	0.1
Transfer Board	0	0
Adjustable Kitchen Stool	2	0.3
Kneeler	0	0
Total 5 Year cumulative		**113.0**

Eastern Region Health Authority –
Northern Area Health Board

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	3	1.6
Shower Seat	8	1.2
Toilet Raiser	2	0.1
Toilet Frame	2	0.3
Bath Seat	2	0.1
Walk-In Shower	9	31.5
Powered Bath Lift	6	4.6
Bed Room		
Mattress Variator	2	1.9
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	6	17.1
Respirator	1	6.0
Mobility Aids		
Wheelchair Powered	9	29.3
Wheelchair Manual	8	5.1
Wheelchair Transit	3	1.2
Wheelchair Cushion	11	1.7
Gel Cushion	4	2.0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	4	1.9
Shopping Scooter	2	7
Walker	1	0.2
Tripod	2	0.1
Calliper	6	6.0
Spine Brace	0	0
Other Brace	2	0.1
Stair Lift	8	48.0
Car Hoist	1	1.5
Special Shoes	1	0.4
Orthotics For Shoes	2	0.1
Transfer Aid	4	0.2

Eastern Region Health Authority – Northern Area Health Board **(cont.)**

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	12	22.4
Perching Stool	4	0.4
Trolley	2	0.3
Office Chair	2	0.6
Aids to Daily Living		
Dust Pan	1	0
Mat Non slip	4	0
Cutlery	1	0.1
Kettle tilter	3	0.1
Grab Rail	10	0.1
Crutches	4	0.2
Garden Tools	0	0
Hand Reacher	7	0.3
Tights Aid	0	0
Orthopaedic Pillow	1	0
Personal Alarm	1	0.3
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	5	0.1
Transfer Board	3	0.2
Adjustable Kitchen Stool	3	0.4
Kneeler	0	0
Total 5 Year cumulative		**194.8**

Eastern Region Health Authority –
South Western Area Health Board

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	3	1.6
Shower Seat	2	0.3
Toilet Raiser	5	0.2
Toilet Frame	3	0.4
Bath Seat	4	0.2
Walk-In Shower	7	24.5
Powered Bath Lift	3	2.3
Bed Room		
Mattress Variator	1	1.0
Bed Raisers	1	0.1
Bed Rest	1	0.1
Special Bed	3	8.3
Respirator	0	0
Mobility Aids		
Wheelchair Powered	5	16.3
Wheelchair Manual	2	1.3
Wheelchair Transit	0	0
Wheelchair Cushion	8	1.2
Gel Cushion	0	0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	0	0
Shopping Scooter	8	28.0
Walker	1	0.2
Tripod	0	0
Calliper	14	14.0
Spine Brace	1	0
Other Brace	0	0
Stair Lift	2	12.0
Car Hoist	0	0
Special Shoes	18	7.2
Orthotics For Shoes	8	0.3
Transfer Aid	0	0

Eastern Region Health Authority – South Western Area Health Board (cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	4	7.5
Perching Stool	7	0.8
Trolley	4	0.7
Office Chair	0	0
Aids to Daily Living		
Dust Pan	2	0
Mat Non slip	2	0
Cutlery	2	0.2
Kettle tilter	1	0
Grab Rail	9	0.1
Crutches	7	0.3
Garden Tools	0	0
Hand Reacher	4	0.2
Tights Aid	2	0
Orthopaedic Pillow	0	0
Personal Alarm	6	2.1
Pneumatic Bath Lift	1	1.1
Long Handled Shoe Horn	3	0.1
Transfer Board	0	0
Adjustable Kitchen Stool	0	0
Kneeler	1	0
Total 5 Year cumulative		**132.7**

PPSG

MIDLAND HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	7	3.9
Shower Seat	5	0.8
Toilet Raiser	2	0.1
Toilet Frame	0	0
Bath Seat	1	0
Walk-In Shower	8	28.0
Powered Bath Lift	3	2.3
Bed Room		
Mattress Variator	0	0
Bed Raisers	1	0.1
Bed Rest	1	0.1
Special Bed	1	2.8
Respirator	1	6.0
Mobility Aids		
Wheelchair Powered	3	9.8
Wheelchair Manual	3	1.9
Wheelchair Transit	0	0
Wheelchair Cushion	3	0.5
Gel Cushion	2	1.0
Non Puncture Tyres Power Chair	1	3.5
Portable Ramp	0	0
Shopping Scooter	7	24.5
Walker	1	0.2
Tripod	0	0
Calliper	5	5.0
Spine Brace	1	0
Other Brace	0	0
Stair Lift	1	6.0
Car Hoist	0	0
Special Shoes	8	3.2
Orthotics For Shoes	4	0.2
Transfer Aid	0	0

MIDLAND HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	0	0
Perching Stool	10	1.1
Trolley	7	1.2
Office Chair	2	0.6
Aids to Daily Living		
Dust Pan	6	0.1
Mat Non slip	2	0
Cutlery	1	0.1
Kettle tilter	2	0.1
Grab Rail	7	0.1
Crutches	2	0.1
Garden Tools	6	0.6
Hand Reacher	9	0.4
Tights Aid	2	0
Orthopaedic Pillow	0	0
Personal Alarm	3	1.0
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	3	0.1
Transfer Board	2	0.1
Adjustable Kitchen Stool	2	0.3
Kneeler	3	0
Total 5 Year cumulative		**105.6**

MID-WESTERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	5	2.8
Shower Seat	2	0.3
Toilet Raiser	3	0.1
Toilet Frame	0	0
Bath Seat	3	0.1
Walk-In Shower	5	17.5
Powered Bath Lift	7	5.4
Bed Room		
Mattress Variator	2	1.9
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	1	2.8
Respirator	1	6.0
Mobility Aids		
Wheelchair Powered	2	6.5
Wheelchair Manual	4	2.6
Wheelchair Transit	0	0
Wheelchair Cushion	0	0
Gel Cushion	0	0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	1	0.5
Shopping Scooter	2	7.0
Walker	1	0.2
Tripod	0	0
Calliper	4	4.0
Spine Brace	0	0
Other Brace	0	0
Stair Lift	3	18.0
Car Hoist	1	1.5
Special Shoes	7	2.8
Orthotics For Shoes	7	0.3
Transfer Aid	1	0.1

MID-WESTERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	3	5.6
Perching Stool	4	0.4
Trolley	2	0.3
Office Chair	2	0.6
Aids to Daily Living		
Dust Pan	6	0.1
Mat Non slip	3	0
Cutlery	0	0
Kettle tilter	0	0
Grab Rail	11	0.1
Crutches	0	0
Garden Tools	6	0.6
Hand Reacher	3	0.1
Tights Aid	2	0
Orthopaedic Pillow	4	0.1
Personal Alarm	1	0.3
Pneumatic Bath Lift	2	2.1
Long Handled Shoe Horn	2	0
Transfer Board	0	0
Adjustable Kitchen Stool	1	0.1
Kneeler	4	0
Total 5 Year cumulative		**91.2**

PPSG

NORTH EASTERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	1	0.6
Shower Seat	1	0.2
Toilet Raiser	0	0
Toilet Frame	2	0.3
Bath Seat	2	0.1
Walk-In Shower	3	10.5
Powered Bath Lift	0	0
Bed Room		
Mattress Variator	0	0
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	0	0
Respirator	0	0
Mobility Aids		
Wheelchair Powered	0	0
Wheelchair Manual	1	0.6
Wheelchair Transit	0	0
Wheelchair Cushion	0	0
Gel Cushion	0	0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	0	0
Shopping Scooter	0	0
Walker	0	0
Tripod	4	0.3
Calliper	1	1.0
Spine Brace	0	0
Other Brace	1	0
Stair Lift	0	0
Car Hoist	0	0
Special Shoes	0	0
Orthotics For Shoes	0	0
Transfer Aid	0	0

NORTH EASTERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	0	0
Perching Stool	3	0.3
Trolley	0	0
Office Chair	0	0
Aids to Daily Living		
Dust Pan	2	0
Mat Non slip	0	0
Cutlery	0	0
Kettle tilter	1	0
Grab Rail	6	0.1
Crutches	0	0
Garden Tools	0	0
Hand Reacher	2	0.1
Tights Aid	0	0
Orthopaedic Pillow	0	0
Personal Alarm	0	0
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	1	0
Transfer Board	0	0
Adjustable Kitchen Stool	0	0
Kneeler	0	0
Total 5 Year cumulative		**14.1**

NORTH WESTERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	3	1.6
Shower Seat	2	1.2
Toilet Raiser	1	0.1
Toilet Frame	0	0
Bath Seat	1	0
Walk-In Shower	9	31.5
Powered Bath Lift	0	0
Bed Room		
Mattress Variator	0	0
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	0	0
Respirator	1	6.0
Mobility Aids		
Wheelchair Powered	0	0
Wheelchair Manual	1	0.6
Wheelchair Transit	0	0
Wheelchair Cushion	0	0
Gel Cushion	0	0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	1	0.5
Shopping Scooter	0	0
Walker	0	0
Tripod	0	0
Calliper	5	5.0
Spine Brace	0	0
Other Brace	2	0.1
Stair Lift	5	30.0
Car Hoist	0	0
Special Shoes	4	1.6
Orthotics For Shoes	2	0.1
Transfer Aid	0	0

NORTH WESTERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	0	0
Perching Stool	6	0.6
Trolley	2	0.3
Office Chair	0	0
Aids to Daily Living		
Dust Pan	0	0
Mat Non slip	1	0
Cutlery	0	0
Kettle tilter	0	0
Grab Rail	11	0.1
Crutches	0	0
Garden Tools	0	0
Hand Reacher	0	0
Tights Aid	0	0
Orthopaedic Pillow	0	0
Personal Alarm	1	0.3
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	1	0
Transfer Board	0	0
Adjustable Kitchen Stool	0	0
Kneeler	0	0
Total 5 Year cumulative		**78.9**

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SOUTH EASTERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	9	5.0
Shower Seat	3	0.5
Toilet Raiser	5	0.2
Toilet Frame	4	0.6
Bath Seat	8	0.4
Walk-In Shower	13	45.5
Powered Bath Lift	6	4.6
Bed Room		
Mattress Variator	2	1.9
Bed Raisers	1	0.1
Bed Rest	2	0.1
Special Bed	4	11.4
Respirator	0	0
Mobility Aids		
Wheelchair Powered	7	22.8
Wheelchair Manual	6	3.8
Wheelchair Transit	4	1.6
Wheelchair Cushion	3	0.5
Gel Cushion	3	1.5
Non Puncture Tyres Power Chair	2	7.0
Portable Ramp	0	0
Shopping Scooter	1	3.5
Walker	0	0
Tripod	3	0.2
Calliper	18	18.0
Spine Brace	1	0
Other Brace	0	0
Stair Lift	2	12.0
Car Hoist	0	0
Special Shoes	17	6.8
Orthotics For Shoes	13	0.5
Transfer Aid	0	0

SOUTH EASTERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	8	14.9
Perching Stool	8	0.9
Trolley	5	0.9
Office Chair	3	0.9
Aids to Daily Living		
Dust Pan	3	0.1
Mat Non slip	3	0
Cutlery	1	0.1
Kettle tilter	4	0.1
Grab Rail	11	0.1
Crutches	5	0.2
Garden Tools	5	0.5
Hand Reacher	9	0.4
Tights Aid	3	0
Orthopaedic Pillow	1	0
Personal Alarm	0	0
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	4	0.1
Transfer Board	0	0
Adjustable Kitchen Stool	4	0.7
Kneeler	0	0
Total 5 Year cumulative		**168.2**

SOUTHERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	8	4.4
Shower Seat	4	0.6
Toilet Raiser	2	0.1
Toilet Frame	3	0.4
Bath Seat	2	0.1
Walk-In Shower	7	24.5
Powered Bath Lift	3	2.3
Bed Room		
Mattress Variator	1	1.0
Bed Raisers	1	0.1
Bed Rest	0	0
Special Bed	1	2.8
Respirator	0	0
Mobility Aids		
Wheelchair Powered	6	19.5
Wheelchair Manual	7	4.5
Wheelchair Transit	0	0
Wheelchair Cushion	0	0
Gel Cushion	2	1.0
Non Puncture Tyres Power Chair	0	0
Portable Ramp	1	0.5
Shopping Scooter	1	3.5
Walker	1	0.2
Tripod	0	0
Calliper	6	6.0
Spine Brace	1	0
Other Brace	2	0.1
Stair Lift	3	18.0
Car Hoist	2	3.0
Special Shoes	10	4.0
Orthotics For Shoes	15	0.6
Transfer Aid	0	0

SOUTHERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	2	3.7
Perching Stool	6	0.6
Trolley	2	0.3
Office Chair	0	0
Aids to Daily Living		
Dust Pan	1	0
Mat Non slip	2	0
Cutlery	0	0
Kettle tilter	1	0
Grab Rail	9	0.1
Crutches	3	0.1
Garden Tools	2	0.2
Hand Reacher	3	0.1
Tights Aid	1	0
Orthopaedic Pillow	0	0
Personal Alarm	2	0.7
Pneumatic Bath Lift	0	0
Long Handled Shoe Horn	7	0.1
Transfer Board	0	0
Adjustable Kitchen Stool	1	0.1
Kneeler	0	0
Total 5 Year cumulative		**103.4**

WESTERN HEALTH BOARD

	Cumulative 5 year units	Cumulative 5 year € '000
Bathroom Equipment		
Shower Chair	13	7.2
Shower Seat	5	0.8
Toilet Raiser	6	0.2
Toilet Frame	5	0.8
Bath Seat	12	0.6
Walk-In Shower	15	52.5
Powered Bath Lift	5	3.8
Bed Room		
Mattress Variator	0	0
Bed Raisers	0	0
Bed Rest	0	0
Special Bed	7	19.9
Respirator	1	6.0
Mobility Aids		
Wheelchair Powered	12	39.0
Wheelchair Manual	7	4.5
Wheelchair Transit	0	0
Wheelchair Cushion	0	0
Gel Cushion	0	0
Non Puncture Tyres Power Chair	4	14.1
Portable Ramp	1	0.5
Shopping Scooter	1	3.5
Walker	1	0.2
Tripod	1	0.1
Calliper	3	3.0
Spine Brace	1	0
Other Brace	2	0.1
Stair Lift	6	36.0
Car Hoist	0	0
Special Shoes	1	0.4
Orthotics For Shoes	3	0.1
Transfer Aid	1	0.1

WESTERN HEALTH BOARD (Cont.)

	Cumulative 5 year units	Cumulative 5 year € '000
Kitchen Living Area		
Special Chair	8	14.9
Perching Stool	8	0.9
Trolley	5	0.9
Office Chair	1	0.3
Aids to Daily Living		
Dust Pan	0	0
Mat Non slip	1	0
Cutlery	0	0
Kettle tilter	0	0
Grab Rail	23	0.3
Crutches	1	0
Garden Tools	3	0.3
Hand Reacher	8	0.4
Tights Aid	0	0
Orthopaedic Pillow	0	0
Personal Alarm	2	0.7
Pneumatic Bath Lift	2	2.1
Long Handled Shoe Horn	4	0.1
Transfer Board	2	0.1
Adjustable Kitchen Stool	0	0
Kneeler	2	0
Total 5 Year cumulative		**214.1**

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OTHER REFERENCE SOURCES

A list of other references and links can be found by visiting the Post Polio Support Group website:

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