

Health Literacy Policy and Strategy

Research Report

for

National Adult Literacy Agency

August 2002

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edited by Jennifer Lynch, NALA Health Project Co-ordinator

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Foreword

This health literacy research report marks the first time literacy has significantly entered the health debate in Ireland. Adult literacy learners have been given a voice. Up to this point in our campaigning work we have had to rely on anecdotal stories about how literacy impacted on people's health encounters and recount international findings. There is a serious lack of Irish research data on this subject available to policy makers. However the Irish results of the 1997 International Adult Literacy Survey (IALS) found that 25% of the population tested could not fully understand the directions on a popular headache packet. This led to the first National Adult Literacy Strategy and a broad recognition that there is a significant minority of Irish adults with literacy problems. The publication of the National Health Promotion Strategy in 2000 which clearly identified low literacy skills as a barrier to good health, illustrates this point:

“poor literacy skillslimits access to health information and health service.” (p.20)

To ensure the strategic effectiveness of the National Health Promotion Strategy 2000-2005 NALA recognised that policy-oriented research was urgently required. We approached the Department of Health and Children in 2000 arguing there was a need for a co-ordinated research programme of study into health and literacy in Ireland. We wanted to establish the precise health issues and needs of low literacy populations and inform strategic policy making.

This research shows that people have struggled with essential health information, consent forms, have not fully understood procedures, found signage confusing and did not feel capable of taking part in decision making. Fear is a big barrier to communication. True patient education is difficult to achieve among people with low literacy skills when there is such a reliance on the written word.

This report also highlights examples of people finding it difficult and in some cases impossible to navigate their way around the health system. To quote one USA researcher: “ Functional literacy is not just about your health, but about how to get to your appointment.” This research illustrates that health literacy means more than just reading information. It involves taking part in decision making and understanding options. Patients need time to review material. Health practitioners need to understand that one leaflet cannot accommodate the whole patient population.

Health practitioners were surprised at the extent of the literacy problem in Ireland and the fact that literacy could be such a significant barrier. We are not surprised that adults do not draw attention to their literacy deficits. We know that people with literacy difficulties become very adept at hiding their difficulties. This means that it will not always be apparent to health practitioners that instructions and advice are not being adequately relayed to low literacy patients.

We hope that this research project will play a part in addressing the health literacy issue. We hope it will focus policy makers and bring literacy and health practitioners together. This is a very exciting time in the Irish medical service. The new health strategy emphasises the integration between primary care and specialist services in the community. There is a strong focus on providing care in

the community. Numerous proposals are made including improved linkages within and between health services. Literacy and health practitioners, especially Health Promotion practitioners could widen the debate on health and communication.

The Health Promotion Unit in the Department of Health and Children financed this two stage project and we would like to acknowledge their initiative. The next step in this project is to produce literacy friendly booklets. We will be guided by this research and hope it will be a meaningful piece of work for Health Promotion and VEC Adult Literacy Organisers. Individual health practitioners in different health care settings have been trying to tackle this issue in isolation with no guidance from management. The VEC adult literacy service has to give health care workers practical help and support. Through our strategic plan 2001-2006 health initiatives we will continue to develop health literacy policies and resources.

Interviews with the 78 adults point to the fact that literacy is not an isolated problem but usually part of a range of social problems. This shows that literacy needs to be viewed and tackled from a wide perspective. While we were particularly interested in how weak literacy skills can be a barrier to good health promotion, discussions with interviewees opened up wider debates. Health literacy is a complex problem that requires a range of responses, hence our range of recommended strategic actions.

The Health Strategy (2001) emphasises the need for a strategic change around how the health system is experienced by the public. We hope this report will contribute to this change.

A handwritten signature in blue ink that reads "Jennifer Lynch". The signature is written in a cursive, flowing style.

Jennifer Lynch
NALA Health Project Co-ordinator

Introduction and Context

“Functional health literacy involves more than simply understanding written and oral communication about health. Functional health literacy is the ability to use written and oral material to function in health care settings and maintain one’s health. It also includes the necessary skills to ask for clarification.”

(based on Rima Rudd’s definition 1999)

This project was commissioned by the National Adult Literacy Agency to research and draw up a health-literacy policy and strategy document. This report is part of an overall three year research project (2001-2004) which aims to develop:

1. a strategy document to advance health education and health promotion among low literacy Irish public and
2. a health education pack or packs for use by educators, particularly health educators, with low literacy populations in a variety of settings.

This report is written under the following chapters:

Introduction and Context

Chapter 1 Literature review

Chapter 2 The research – literacy students/patients

Chapter 3 The research- health professionals and Health Promotion staff

Chapter 4 Conclusions

Chapter 5 Health Literacy Policies and Strategies

The Context

Purpose of study

The purpose of this study is to develop a draft policy document on health education and promotion for low literacy populations, based on a strategic document. Both the strategic document and policy document will be based on the findings from qualitative research with low literacy students/patients and health professionals and Health Promotion staff. These are, in turn, meant to support and ensure the effectiveness of many aspects of the National Health Promotion Strategy 2000-2005.

VEC literacy schemes

While literacy tuition takes place in a wide range of settings the VECs are the main providers of adult literacy in Ireland. Each VEC employs an Adult Literacy Organiser who is the local point of contact for the general public.

National Adult Literacy Agency

NALA is a non-profit membership organisation concerned with co-ordination, training and policy formation in the adult literacy sector in Ireland.

NALA's mission statement is:

"To ensure all adults with literacy difficulties have access to a range of high quality learning opportunities."

Extent of weak literacy skills in Ireland

25 % of the Irish adult population is at Level One on the literacy levels, as defined by the IALS. This level indicates very low literacy skills, where the individual may, for example, have difficulty identifying the correct amount of medicine to give a child from the information found on the package.

30% are at Level Two. Those at Level Two have been identified by the survey as people who can only deal with material that is simple, clearly laid out and in which the tasks involved are not too complex.

These two levels of literacy are not just about the ability to read and write. Low literacy has implications for the way people think about themselves and their environment. It has implications for people's capacity to take in information about the world around them and make sense of that information. For example, a literate person can read a bus timetable and take directions to finding the bus station. The cognitive ability to process this data is not so well developed in a person with low literacy skills.

International research has proven the close relationship between literacy and health status. The Organisation for Economic Co-operation and Development (OECD) sponsored International Adult Literacy Survey, (IALS): Learning in the Information Age pointed out that:

"People with higher educational attainment have healthier habits and lifestyles, and are more educated towards the management of their own health through access and understanding of information and preventative health practices."

There is a very little Irish data on health literacy and health status. The little data available to us however has shown that:

- One in four Irish adults between the ages of 16 and 66 years have very poor literacy skills and cannot satisfactorily read the instructions on medication (IALS, 1997).
- according to IALS over half of Irish adults (53%) are not functionally literate in today's modern society. This means that people scored below the minimum desirable threshold in Western societies.
- An estimated 17.4% of respondents in the 1999 Survey of Lifestyle Attitudes and Nutrition (SLAN) survey were not able to read and understand information and this prevented them from improving their general health. 6.4% of respondents also reported that they think their health would be better if they had easier to read health information.
- The Food Safety Authority (1998) reported that people in the lower socio-economic classes were less likely to follow manufacturers' instructions for storage of food (25% sometimes and 14% rarely/never) in comparison with people from higher socio-economic classes (12% sometimes and 8% rarely/never).

Health literacy as a practice in the USA has developed in the past fifteen years through a process of hybridisation between health professionals and community educators. To bring about a resolution to this problem, collaboration between these disciplines is needed. In the words of Dr Rima Rudd, a pioneer in the field of health literacy:

“Health literacy is a new concept that is getting a good deal of attention. ...Educators, researchers and practitioners can work together to explore strategies for improving communication, increasing needed skills and fostering efficacy.”

In this report national strategic documents are reviewed, as are the international and national research publications as well as some interesting practical documents. The final chapter includes policy statements and strategies to make policy suggestions realities.

Health Promotion in Ireland

The Health Promotion Unit within the Department of Health and Children is responsible for the development of health promotion policy. Since its establishment in 1988, following the closure of the Health Education Bureau, the Unit has discharged a dual remit of policy development, research and evaluation on the one hand with awareness raising of lifestyle issues through multi media campaigns and the development of materials for the public.

Since the development of the first Health Promotion Strategy in 1995, there has been an increased emphasis on health promotion in settings such as schools, hospitals, and the community. This includes the identification of key target groups, with a view to developing interventions to meet their particular needs.

The National Health Promotion Strategy 2000 – 2005 identifies health promotion as both a policy matter and an operational issue. The Department of Health and Children are responsible for the policy development of health promotion.

One significant development of the Unit had been the establishment of Health Promotion departments within all health boards, led by Health Promotion Managers who have a dedicated budget and staff. The operational aspect of health promotion has been delegated to the Health Promotion Units located in the Health Boards.

The Research

Methodology

This is a qualitative research project designed to discover the barriers to health literacy. The methodology used included:

- Interviews and discussion groups with literacy students in groups. These groups are representative of the target groups named in the National Health Promotion Strategy 2000-2005. These are:
 - Children
 - Young people
 - Women
 - Men
 - Older people.

The issues related to children were discussed with groups that included mothers and fathers and grandparents.

- Interviews with health professionals and administrators drawn from the operational levels of the health service. These interviews were carried out on a one to one basis and in groups.
- A literature search and review of best practice and practical examples of health literacy education.

Target groups

The low literacy patient groups were interviewed in eight groups.* Groups varied in size from five to twelve persons. Seven of the low literacy groups were drawn from programmes that are directly connected with literacy programmes. Four groups were drawn from Dublin city, three groups were drawn from Limerick city and one group from Co Offaly. One group was made up of adults from a VTOS scheme.

Interviews

The eight groups were interviewed in a setting and method that generated a similar pattern of response so comparisons could be made. The purpose of the study was presented to the group. Following any questions of clarification, each participant was invited to speak in turn, giving their name and a small piece of relevant information. People sometimes for example gave the number and ages of their children.

Two questions were put to each group:

1. they were asked to discuss good experiences they have had in relation to contact with health professionals; and
2. they were asked to focus on difficult situations they had experienced.

They were also shown a number of health promotion leaflets which were used to spark debate.

Out of this discussion it becomes clear that there were a range of issues that could be termed: health information, treatment procedures, prevention and emotional experience of good and difficult experiences. The impact of literacy difficulties was then teased out in the discussion around these issues.

The Health Professionals: Respondents

Health professionals interviewed included hospital doctors, general practitioners, outpatient nurses, out patient nurse managers, public health nurses, a hospital pharmacologist, a commercial pharmacologist, a pharmacology technician, clinical nurse managers and a Health Promotion Officer.

Research meetings were conducted individually and in groups. Research interviews with health professionals were constructed on a set of questions. These questions were framed after the group interviews with patients. In this way the action process of this study also had an iterative element in that the output from the low literacy patient groups has influenced the formation of the discussion with the health professionals. (See Power Model at Appendix B)

* The term literacy student and patient with literacy difficulties will be used interchangeably in this study.

Health is a complex service. This complexity is reflected in the range and numbers of health professionals engaged in delivering health care to the patient. At the centre of this study is the interaction between the patient and their health professional or stakeholder.

Meetings were based on six questions:

1. What input do you have into health promotion?
2. Have you awareness about literacy levels with your patients?
3. How often would you have to use documentation with your patients ?
4. If often – what kind?
5. What would make it difficult for you to explain health care to low literacy patients?
6. General discussion around health literacy.

Data from the NALA Literacy Awareness Training pack was introduced to the meeting at appropriate points in the interview. This pack introduces people to literacy statistics in Ireland. The five IALS levels of literacy were described to the health professional. (See Appendix A)



Chapter 1

Literature Review

1. National literature
2. Nala Resources which could be used by health practitioners
3. International literature

1

Chapter 1: Literature Review

The literature review is presented under the following headings:

1. National Literature
2. NALA publications which could be used by health practitioners.
3. International Literature

1. National Literature

The documents that are reviewed here are the following;

- National Health Promotion Strategy 2000- 2005
- National Health Strategy 2002
- Towards an Equality and Rights based Health Care System - Submission by the Community and Voluntary Pillar 2001
- NALA's submission to the National Anti Poverty Strategy (NAPS) Working Group on Health 2001
- The National Youth Health Programme – Mapping the Journey – An evaluation of the Health Promotion Youth Service Initiative 1999/2000
- Traveller Health – A National Strategy 2002 – 2005
- SLAN survey 1999
- Access to Health Care Information Services in Ireland 1995
- Health Illiteracy – The Hidden Handicap 2001

National Health Promotion Strategy 2000- 2005



This document establishes the policy framework at government level. The purpose of this strategic document is to set out the broad policy framework, which aims to promote a holistic approach to health. It states that:

“poor literacy skills ...limits access to health information and health services.”(p. 20)

TARGET GROUPS

The target groups identified in this National Health Promotion document are:

- Children
- Young People
- Women
- Men
- Older people.

This report identified the following as essential for a successful strategy:

- Developing a health proofing policy
- Strengthening partnerships
- Establishing a National Health Promotion Forum
- Reorienting the health services
- Supporting research, monitoring and evaluation
- Strengthening regional health promotion structures
- Consulting with the consumer.

This document emphasises that for the strategic aims of the strategy to be implemented, inter-departmental links must be strengthened.

“Establishing health alliances involves consultation with, and participation of, all partners to address the social, economic and environmental determinants of health. It is important that non-health sectors become aware of the capacity to contribute and that their involvement in health promotion interventions is encouraged and supported.” (p.64)

Quality and Fairness – a Health System for You – 2001- 2010 Health Strategy (2001)



This document presents a new philosophy towards health, which is both challenging and exciting. A whole system approach is presented that incorporates:

This vision is in tandem with that laid out in the National Health Promotion Strategy 2000-2005. These central themes are reiterated throughout the document lending credibility to a view that a serious view of delivery standards is now firmly in the health agenda.

ACHIEVING THE VISION

It sets out the priority goals and the means of achieving them. It also includes a detailed action plan and lists strategic actions. In keeping with the stated aim to maintain standards and improve them, it includes a programme for monitoring and evaluating the outcomes of the plan.

PEOPLE AT THE CENTRE OF THE VISION

What is proposed is a people centred system. This means one that it is fair and can be trustworthy. The key statement here is a system that “ helps individuals to participate in decision makingwill empower people to be active participants in decisions about their health.” Issues of eligibility and access to health services are identified as crucial in this document.

Four goals are identified for government policy:

1. Better health for everyone
2. Fair access
3. Responsive and appropriate care delivery
4. High performance.

COMMITMENT FROM GOVERNMENT

The strategy also aims to eliminate barriers for disadvantaged groups to achieve healthier lifestyles. There is also commitment in this document to fully implementing the National Health Promotion Strategy. Taking these two points together a seamlessness is emerging in the Department of Health and Children's strategic planning.

Towards an Equality and Rights Based Health Care System (2001)

This document published May 2001, is a collection of submissions received from members of the Community and Voluntary Pillar.* It incorporates the holistic and visionary perspective of the national health strategy document.

This document looks strategically at the barriers people encounter accessing the health services and health information. It sees access to health services and health information as a human right. Included in this submission is a range of proposed models that could improve access.

DETERMINANTS OF POSITIVE AND NEGATIVE HEALTH OUTCOMES

Among some of those positive determinants are education and clear access to appropriate information. Some of the negative determinants are poverty, educational disadvantage, and a medical model with limited reference to social and economic context.

HEALTH BARRIERS

Among some of the barriers listed are unsympathetic practitioners and a lack of suggested improvements. Among some of the ways that things could be improved are user-friendly material, advertising of services in people's own environment and one-stop shops.

Submission by National Adult Literacy Agency to the National Anti Poverty Strategy Review Working Group on Health March 2001.

In this submission NALA acknowledge that people with literacy difficulties can experience difficulties in a range of areas their lives, including the workplace, the home, and in health care settings. It outlines how individuals are running into trouble in different health care settings which includes such issues as understanding:

- Appointment slips
- Medical brochures
- Consent forms
- Doctor's directions
- Gaining access to services
- Proper use of medication
- Managing self care.

*The Community and Voluntary Pillar is made up of representatives from seven national organisations including the Community Platform. The Platform is made up of 25 national organisations involved in combating poverty and disadvantage. It was formed in 1996 to co-ordinate the sector's involvement in negotiations at a national level.

It makes nine recommendations. (Appendix C outlines the recommendations in more detail)

RECOMMENDATIONS

- assign a health literacy budget
- provide literacy awareness training for health professionals
- integrate health literacy into medical training
- use Plain Language
- literacy practitioners should work with health practitioners to develop a health and literacy curriculum
- use more frequently signs and symbols that have national /international recognition e.g. disabled sign
- establish a national health literacy research board
- run a national publicity advertising campaign aimed at patients with weak literacy skills
- establish a research project to quantify how much older people are experiencing health literacy problems.

The National Youth Health Programme – Mapping the Journey – An evaluation of the Health Promotion Youth Service Initiative 1999/2000.

This document is a summation of the Health Promotion Youth Service Initiative (HPYSI). The aim of this programme was to encourage and support youth organisations, to plan, implement and evaluate an organisation wide approach to promoting health in youth work settings. The initiative was designed to provide youth organisations with a support and training framework to carry out this initiative.

OUTCOMES FROM THIS PROJECT

The benefits and challenges for involvement in the initiative can be summarised as creating a dynamic holistic model of exchanging information and knowledge. In addition to the training project the report suggests that a regional multi agency approach would result in greater commitment at local level to improving health promotion practice.

An interesting piece of learning from this project is that the training model:

“...placed a disproportionate emphasis on training as the only model of integrating health promotion in to youth organisations.”

The report suggests that the structure of future initiatives “need to redress this by designing additional models and approaches for putting health promotion and policy and practice on the Youth work agenda.”

Traveller Health - A National Strategy 2002- 2005

The focus of this document is action not analysis. This document has resulted from the Task Force for Traveller Health in 1995 followed by the Traveller Health Advisory Committee report 1998 and now it has culminated in this strategic document.

This is a valuable document that looks specifically at the needs of Travellers and

their health needs. Literacy difficulties are very much part of the barriers experienced by this group in relation to health matters. The capacity to understand health promotion and prevention is restricted by the high level of literacy difficulty (estimated up to 80%). Travellers have difficulty in understanding instructions for self care and administration of appointments due to literacy problems. There is reluctance to visit the public health nurse due in part to low literacy levels.

The creative solutions proposed include:

- Health Boards will ensure that health promotion programmes are culturally sensitive and appropriate and recognise the particular constraints under which many Travellers live.
- Posters and videos should be chosen as against leaflets.
- Appointment of specific resource personnel to support traveller health.
- Training for health staff who regularly come into contact with the Traveller population.
- Department will work with University Department's of General Practitioner in promoting any educational, training or promotional programmes to highlight issues of travellers' health.

Two important Irish surveys

SLAN (Survey of Lifestyle Attitudes and Nutrition) 1999

The first national survey of Irish people's attitudes to nutrition, lifestyle and health was undertaken by the Department of Health Promotion at National University of Ireland (NUI) Galway in 1998. Published in 1999 it highlighted social variations in health and lifestyle behaviours between the lower and higher socio-economic groups. It is apparent from the SLAN survey that healthier choices are less easy for those in lower socio-economic groups.

Two findings were of particular relevance to NALA's campaigning work:

1. An estimated 17.4% of respondents in the SLAN Survey were not able to read and understand information and this prevented them from improving their general health.
2. 6.4% of respondents also reported that they think their health would be better if they had easier to read health information.

Access to Health Care Information Services in Ireland (1995)

In the mid 90s, this survey was carried out by Jennifer Mc Dougal, for the Library Association of Ireland. The Department of Health and Children commissioned this survey which set out to determine the information needs of health care professionals, managers and the public. Twelve recommendations were made in relation to the improvement of information management for health professionals. This document also recommended the development of a policy to improve the provision of health care information for the public, patients and their carers. One of the recommendations has direct implications for health literacy:

"Foster and improve communications and information exchange with voluntary organisations including self help groups, charities and other information providers."

Health Illiteracy* – The hidden handicap - Dr Paul Grassby, Director ICCPE 2001

This article while addressed to pharmacists also has a value for all health care professionals. The negative impact of literacy difficulties on a patient's capacity 'to obtain, process, understand and act upon basic health information' is stated. This article lists some of the practices that have been developed in USA and the UK.

Dr Grassby tells us that the USA government, for example, has mandated that all health care communications directed to patients be simplified to a level that the majority of patients can understand and act upon. Dr Grassby suggests that the success of the tabloid newspapers in being readable to a broad population has lessons for the use of plain English in health literature. In conclusion he refers to the need for phonetic pronunciation listed in Mosby's Medical Drug reference, which give phonetic pronunciations of all drugs listed.

2. NALA Resources which could be used by health practitioners

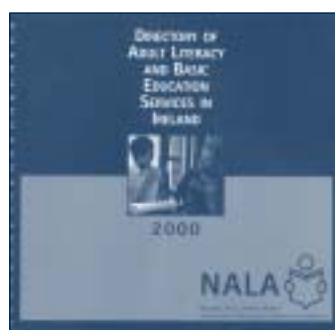
NALA has four publications worth mentioning here.

Writing and Design Tips (1999)



This is a practical short booklet that advises on how to write and design material using plain language guidelines, published in 1999 with a grant from Comhairle. All plain language guidelines are explained and illustrated. This booklet has been distributed to a number of health practitioners including pharmacists. It has proved to be a very useful resource for individuals writing for the general public who want to accommodate individuals with weak literacy skills.

NALA Directory (2000)



The local literacy service run by each VEC is explained in this directory. It outlines the service offered by each literacy scheme along with contact details. As this information needs constant updating referral leaflets offering basic contact details are frequently published. The directory and leaflets are distributed to all referral networks and would prove very useful for health practitioners who wish to contact their local literacy scheme.

* NALA does not use the term illiteracy as its members prefer the terms adult literacy or adult basic education.

NALA Information Pack (2000)



This publication explains:

- the extent of literacy in Ireland and the definition used by NALA
- the causes of weak literacy skills
- how local literacy scheme works and
- explains some projects run by NALA.

This publication would prove useful for any group wishing to know more about adult literacy.

Access and Participation in Adult Literacy Schemes (1998)



Over a two year period NALA explored the problem of non-participation and sought to identify strategies which could be used by literacy providers to recruit potential students, by drawing on the experiences of adults currently availing of tuition.

This survey by Inez Bailey and Ursula Coleman identifies barriers similar to those named by the respondents in this health study.

3. International Health Literacy Research

The following are the international documents reviewed in this report.

1. Empowerment Health Education in Adult Literacy: Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. By Marcia Drew Hohn, Ed.D.
2. A Maturing Partnership. Publication Focus on Basics: Vol 5' Issue C, February 2002
3. Pfizer Journal: Responding to the Challenge of Health Literacy, 1998.
4. Teaching Patients with Low Literacy Skills. Second Edition. By Cecilia C. Doak, Leonard G. Doak and Jane H. Root.

Empowerment Health Education in Adult Literacy: Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. By Marcia Drew Hohn, Ed.D.

This is a document that tells the story of an action learning project over a period of time. Its aim was to look at the connection between low literacy and poverty and through the action project devise ways forward. It is divided into four sections:

1. The context of literacy levels and health status. A look at the current practice of promotion.
2. Participatory action research.
3. Learning - empowerment and power sharing.
4. Implication of policy and funding.

It is interesting that this report declares the following:

“Health education and health promotion activities are accomplished primarily through print material written at tenth grade level by skilled readers for skilled readers.”

In this report Dr Hohn outlines the difficulty in approaching solutions in the form of: “Beefing up’ literacy skills in the community or “Fixating” on developing low literacy materials that would be readable for most adults.

Another approach could be to develop new ways for health information to communicate, ranging from simple strategies such as drawings and tape recordings to more complex techniques such as interactive video. Dr Hohn argues that each of these approaches have a role and subsequently warns us that the problem is too complex to be addressed by any one approach. She is supported by the USA research, which affirms the need to view this as a problem requiring an interdisciplinary approach.

In addition this interdisciplinary approach needs to be applied holistically to the low literacy patient groups but also to the health professionals. This links to the underlying principle of a holistic approach proposed by the submission of the Community and Voluntary Pillar to the National Anti Poverty Strategy. It also could be argued this is reflected in the current Government strategy which advocates a multi - disciplinary and multi - sectoral approach to health.

MULTI DISCIPLINARY APPROACH

Dr Hohn’s methodological approach of participatory action research is an appropriate method to tackle this issue. She summarises the learning from the action research as follows:

- Adult literacy programmes are a good place to learn about health
- Students listened to and trusted student teachers
- Students saw health as an important issue
- This was a leadership vehicle for the students
- It was a social space to talk about health
- Health topics facilitated and motivated literacy learning

A Maturing Partnership by Dr Rima Rudd. Publication Focus on Basics: February 2002, Vol 5, Issue C , NCSALL*

Dr Rima E Rudd Sc.D. is Director of the Harvard School of Public Health. This publication is a comprehensive article of the history of health literacy in the USA. Health and literacy have come together to form a hybrid area of study. The link between socio economic status and health has now been made. Several milestone reports and events are listed in this article that demonstrate this. This is a very helpful article in that it draws the line from the early beginnings of the development of health literacy to the present in the USA.

HISTORY OF HEALTH LITERACY RESEARCH IN USA

The Secretary of Health and Human Services prepares an annual report to the President and Congress on national trends in health statistics. The 1998 report focused specifically on socio-economic status and health. The 1993 National Adult Literacy Survey was ground breaking in that it showed that 47 – 51 % adults scored in the lower range of this study. This triggered the beginning of research by health professionals.

*NCSALL stands for the National Center for the Study of Adult Learning and Literacy.

LIGHT DAWNING – THE BIRTH OF HEALTH LITERACY

It was felt that health topics in an adult education setting would motivate the adult learner. However the educators realised health was not their field of expertise. This discomfort led to a shift from a focus on health content to a closer examination of literacy skills needed for health related action. This means that the idea of educating the low literacy person will not of itself solve the problem of health literacy. It was discovered that the solution was not just possible for educators alone. There needed to be collaboration between health and education. This is the core of health literacy.

A USA GOVERNMENT COLLABORATION

A partnership between the US Department of Health and Human Services and the developers of the National Assessment of Adult Literacy planned for 2002, led to the inclusion of health related tasks in this second wave of adult literacy assessment. Three new types of information will be included, namely, 'clinical', 'prevention' and 'navigation'. 'Clinical' will include filling outpatient forms and the taking of medication. 'Prevention' will include tasks such as identifying needed change in eating or exercise habits. 'Navigation' will look at tasks related to understanding rights in health care.

Dr Rudd states that the health professionals cannot change the literacy levels of their patient community.

“They can however work to improve their own communication skills, the procedures followed for communicating with and interacting with people, and the forms and materials they write.”

This two-fold approach or strategy of increasing the literacy levels of the adult learner while at the same time increasing the communication skills of the health professional is the way forward.

In conclusion, the concept of developing communication and awareness skills for health professionals is essential for the successful development of the Irish government's vision for health. The lessons from more than ten years of research and action learning as well as a strategic connection between key government agencies and research bodies has led to the understanding that holistic means just that – looking at all sides of the equation. All involved can work together to improve communication.

Responding to the Challenge of Health Literacy, Giorgianni Salvatore J. PharmD Editor-in-Chief, The Pfizer Journal, Spring 1998, Vol 2, No.1

This is a comprehensive paper created by a team of 17 people experienced in the field of adult literacy. It discusses the most up to date research and brings together a description of what needs to be done to bring about future improvements.

COMMUNICATION

Communication is cited as a core issue. There is a detailed discussion of communication and the difficulties in engaging with a patient with literacy difficulties. To summarise this chapter the experts discuss various aspects of the mismatch between the patient and health professional in trying to communicate across a myriad of barriers, such as time pressure, chronic illness and the ensuing vulnerability of the patient and the emotional blocks of fear and shame.

FEELINGS OF SHAME AND FEAR

The emotional impact on adults who cannot read is immense. Added to shame is the feeling of fear. While people are ill they have the added burden of low literacy skills and the whole range of difficulties and painful feelings that accompany this issue. James J Balija, Executive Director of the American Association of Diabetes said that:

'Fear is the main barrier to communication in medicine.'

ECONOMIC BENEFITS

There are real economic benefits to be gained from tackling the issues of health literacy. In relation to the cost of good health Dr Rima Rudd states that:

"Improved health does not have an outrageous cost...these skills can be used within the typical 10 to 15 minutes of dialogue. We should not function under the misconceptions that this is something that is out of reach, expensive or an enormous burden on our system."

This Pfizer report states that this problem could be costing the American Government \$8-\$15 billion per year.

MULTI LINGUAL CHALLENGE

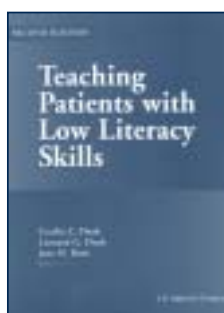
The diversity in language being experienced in contemporary USA is very real. This has led to the need for interpreters in emergency departments. However in some emergency situations non-English speaking patients bring their own interpreter, often recruiting a child to speak for the adult.

'The danger here is that these interpreters are not able to understand or explain the information. The patient winds up with an incomplete picture of the information and resources.'

DEVELOPING READING MATERIALS

The challenge of developing reading material at the lowest possible level, fifth grade level or lower, and explaining technical medical information is alluded to in this publication. Despite the many complexities attached to this challenging issue a comprehensive list of practical guidelines are suggested to the reader. (See Appendix D). Elements of this advice are also incorporated in the draft policy document contained in this report.

Teaching Patients with Low Literacy Skills (1996) Second Edition. By Cecilia C. Doak, Leonord G. Doak and Jane H. Root.



This is a comprehensive and practical teachers guide to the teaching of adults about health literacy. Chapter 1 discusses the context and raises some interesting issues around the common myths about literacy. It also discusses the trends in US health education that address low literacy issues. These trends include the introduction of the Plain Language Laws. Positive changes can also be seen by the introduction of standards laid down by the Joint Commission of Accreditation of Health Organisations under:

- Safe, effective use of medicine
- An effective use of medical equipment
- Potential food drug interactions

This is a practical book that looks at teaching skills and suitability of materials, as well as the comprehension process. It presents guidelines for writing and discusses the rationale for using visuals.

Summary of Literature Review

International research demonstrates that health literacy, a new hybrid of interdisciplinary work, has identified the need to not only develop the self esteem of patients but also to develop the communication skills of health professionals.

The literature review has presented the key Irish policy documents. They outline the policy framework within which health literacy can be accommodated and developed. Included in this review also are a range of informative articles and publications that deal with the Irish situation.

Chapter 2 The Research

Interviews with Adult Literacy Learners

1. Women/Mothers

2. Men/Fathers

3. Young Women and Young Mothers

4. Older Men and Women

2

Chapter 2: The Research

Interviews with Adult Literacy Learners

The following groups were interviewed. These groups mirror the categories or target groups named in the National Health Promotion Strategy 2000 – 2005.

1. Women/Mothers
2. Men/Fathers
3. Young Women and Young Mothers
4. Older Men and Women

The response to the questions from these groups is condensed in this chapter, due to the similarity and overlap between the experiences of the groups in relation to their health experiences. There are of course experiences that are specific to some groups by virtue of their age or geographic location. For example, older women have had more contact with the health services than younger women. The former would have both the experience of women's health issues and also an increase in chronic illnesses as they have become older. The latter primarily were concerned with women's health issues and children's health. For the purpose of this report it is considered valuable to discuss the common issues presented by the women under headings listed at 1 and 6 above. The report will then discuss the issues particular to their age and geographic category.

Positive experiences of interviewees are examples of excellence already to be found within the health services. They can be captured and developed as possible future actions in addition to the recommendations listed in this chapter.

1. Women/Mothers

Group one consisted of Dublin women who are attached to an adult education programme. They ranged in age from 25 – 50. Most of this group were mothers. Group six are older women ranging in age from 40 – 65. What these groups had in common was a heavily reliance on their health professionals at significant times in their lives and during chronic illness. The first group of younger women report more positive experiences than their older counterparts in group six. Good experiences seemed to be very rare for the older woman.

It is useful to investigate the positive and negative experiences these two groups have had when dealing with their health professionals. In some instances it may seem difficult to see how literacy difficulties are conclusively to blame for the failures. I would remind the reader to return to the health literacy definition, which contains within it the reality that a range of issues are contributing to health literacy difficulties besides reading and writing ability.

Positive experiences were reported when mothers spoke about Children's hospitals. The men's group, when discussing their role as fathers, reported similar positive experiences in these hospitals. There were examples of direct caring of the mother by the hospital nursing staff. One mother reported bringing her crying baby to the hospital at night. The nurse she met told her it was teething but

suggested that she leave the baby in the hospital until 8 a.m. the following morning. This was to allow the mother get a nights rest. While this, at first sight, does not seem to have a literacy connection, the relationship of trust developed between the mother and her health care professional made it easier for her to disclose her literacy difficulties.

The Practice Nurse emerges also as a person or professional who was highly praised by the women. One mother described an ideal experience in being educated to manage her child's asthma condition. The mother was shown pictures of lungs to explain what is happening during an asthma attack. The nurse communicated directly with the five year old child, while the mother was present. This increased the child's self esteem which in turn gave the mother a sense of confidence in her role.

'My child felt brilliant'

The nurse also helped the mother actually experience the sensation of an asthma attack by getting her to breathe out and then try and speak. This more than anything allowed the mother to empathise with her child's condition. To cite a relevant quote from the 1998 Pfizer report:

"Just because a person is an unskilled reader does not mean he is not an information seeker."

Linked to the positive experience of this mother was a mother who had a negative experience. Her brother had died from an asthma attack some years previous to this. This, combined with her literacy difficulties, made her experience of learning to manage her infant daughter's asthma traumatic. She found it impossible to access a response from the hospital to help her. She was not even aware of the fact that all the equipment and medication were available on her medical card. Lack of literacy is an important reason why patients sometimes do not fully engage in an exchange with health practitioners.

"It makes me feel powerless to help my child"

Where the parent's self-esteem is low it is unlikely they will be motivated to avail of health promotion literature. This often masks the underlying problem of literacy difficulties.

There is clearly a need for health professionals to develop skills of sensing when a mother is unable to access the appropriate information. NALA's Literacy Awareness Training day would make practitioners more sensitive to this.

Informed consent raised an issue for women of all ages. According to respondents, they do not as a general rule go through consent forms with health practitioners. Discussions with health professionals confirm this. The practice of reading through the consent form with patients is something an individual health professional may decide to do themselves – it is not standard practice. People need time to review material. Literacy practitioners would also argue that a person might be able to read a form, but this does not necessarily mean that they fully understand it.

One mother raised an experience where her infant child had stomach surgery. In what she described as a casual conversation with a nurse after the surgery she learned that her child's appendix was also removed. The purpose of the surgery was to correct a gut condition, not remove her appendix. Prior to her child being finally diagnosed with a twisted gut she had been told she was an over anxious mother. This woman's experience left her feeling angry and undermined. This experience is mirrored in the other groups.

“Functional literacy involves competency in gathering information to evaluate a situation. It is not easy to separate literacy from information gathering or decision making competency.”

Pfizer 1998 report

One older woman admitted that although she had had surgery she still did not know what had been operated on. She did not know which part of her body had been removed. One aspect of poor communication is that low-literate patients cannot fully understand information. In this case the lack of knowledge about her own surgery impacted on her recovery, as she felt quite ashamed at being unable to clearly discuss her needs. As a result of it being discussed in this study, her female friends supported her to return to her doctor. This she has done and is now making a good recovery.

Medical terminology was discussed in all groups, and all groups unanimously said that it causes them problems. Any leaflets containing only medical /scientific terminology is similar to using a foreign language. This can also be an issue for adults with strong literacy skills. They suggested including the layperson’s words. For example, Ophthalmic could have the word EYES beside it. Health promotion leaflets need to be designed more with the audience in mind. In certain instances medical professionals need to be mindful of patients with literacy difficulties. Where leaflets are used as an addition to the face-to-face communication, the health professional may need to go through the material with the patient.

To support the health professional the leaflets need to be patient friendly. There are examples of this such as the asthma’s chart, produced by 3M Corporation which is successfully used by nurses in asthma clinics. A range of health promotion leaflets were shown to all the groups and through discussions they came to the conclusion that leaflets alone will not improve communication.

Discussions with health professionals who exhibited good communication practices with their patients all read through the documentation with their patients to ensure they had a clear understanding of medical instructions. What comes through from discussions is the need to simplify the language, use large print and less medical language or to use it in conjunction with the layperson word if it needs to be there.

Medication and older people is an issue that has been raised by patient groups and health professionals. Women expressed real concern about getting it right. Here they described experiences of poor communication from health professionals where they felt they were actively discouraged from asking questions of the consultant by the nurse. It is interesting to note that some of the older women reported having experiences of complimentary health. The one thing they all liked about the complimentary experience was that they felt truly listened to and empowered as they had engaged in their own health management.

2. Men/Fathers

Two groups of men only contributed to this research. There are men and women represented in the older rural group. However, the study is very grateful to the support of the vocational education sector for inviting and supporting two all male groups to contribute. The response from these groups will be amalgamated from group two and group four, listed at the start of this chapter. The majority of the Dublin based group of men are fathers and ranged in age from 25 – 65. The latter group, from a provincial city consists of young men who ranged in age from 17 – 22. The health issues presented by these groups were impacted in both cases by literacy difficulties. Both these groups are currently engaged in adult education programmes, which incorporates literacy learning as part of their studies.

The older men focused initially on different aspects of the health services as it had affected them. There was discussion of ambulance service failures and mishaps. The younger men raised age specific health issues almost immediately. Accidents, drugs and illnesses specific to their families were discussed. In some instances there were oblique references to alcoholism.

Positive experiences were in the main relayed by the older men. The group had positive experiences of specific general hospitals. They welcomed seeing the Tallaght Hospital's vision statement on the nurse's key rings. Like the women discussed above they too reported good experiences of the Children's Hospitals. One example, reported with enthusiasm by more than one person was the use of children's storybooks specifically designed to support knowledge about conditions such as asthma. One book in particular called, *Desmond Dragon*, is a big favourite with the parents in both groups interviewed. Some parents use this book as bedtime reading with their children who have asthma.

The negative experiences reported and discussed here are worthy of mention. The men named the filling in of forms as being very stressful. A simple question in a form such as first name and family name can be confusing and misleading for a person with low literacy skills. They were also very conscious of the doctor's body language and could be easily made to feel diminished by a doctor reading their notes and not looking at them. The communication behaviour of the health professional can engage the patient in their treatment or put them off altogether.

Again the key element in attracting the men to written material shown was its attractiveness. Pictures on the cover are important. An attractive picture such as a baby could help people pick up leaflets for difficult conditions such as HIV or drugs or alcoholism.

The overall response from the younger men was to include a picture. They also suggested that everyday language such as 'FAGS KILL' would mean more to them than detailed leaflets.

3. Young Women and Young Mothers

The first group are a group of young women between the ages of 17 and 22. They live in a provincial city and are involved in an educational programme, which includes life skills training and literacy learning. The second group were all young mothers ranging in age from 18 – 28. They are a Dublin based group involved in a further education programme. The health issues here were antenatal care although health literacy issues, communication and courtesy were also discussed.

One young woman reported being mistaken as the mother of her two-year-old sister by a hospital nurse. The health professional asked her to stay in hospital with her infant sister assuming she was her mother. This is an example of poor communication, which had the potential to be problematic.

Some of the women were very excited to have their opinions asked. When two women joined the group late they asked their colleagues what the meeting was about. The reply was:

“We want to change the world a little bit”.

They all reported good experiences with the Children’s Hospital. There is an effective quality of communication that is reported by the patient groups occurring with their interactions with the Children’s Hospital.

All the Dublin groups were aware of the Family Planning Clinics and the Well Woman Centre. The women’s experiences of the family planning clinics and that of the Well Woman Centre were models of communication they preferred. This is basic courtesy and consideration, which, in the provision of a cup of tea, communicates to the patient that they are being treated in a respectful dignified and welcoming way. They joked among themselves at their first experience to being treated at the Well Woman Centre:

“I thought the doctor was talking to someone behind me she was so nice”.

Being offered a cup of tea, such a simple thing, left an indelible impression of being cared for in a very particular way. The positive outcome of this was the freedom to trust their health care professional regarding the literacy difficulties.

Both groups reported mixed experiences from maternity hospitals. However, overall it would appear that this Dublin based group had access to a good range of services for their health needs. It was not so for the provincial group.

Overall the researchers experience of the provincial group was that they had a deep mistrust of authority. This in itself would provide a challenge to the communication skills of health professionals. The key to earning their trust is communication. It would be incorrect to say that all the women exhibited this negativity. Some of the women in the provincial group had clearly benefited from being in a small support group. Their educational establishment professionally facilitates this group. They had a confidence about them and their contribution to the material was most useful. Like all the other groups both these groups wanted simplification of language in written material and the removal of jargon.

Communication is the key. The issue here is one of training for health professionals to have the skills to manage the relationship development with these young women to support a more positive view of their health.

4. Older Men and Women

This group presented a range of issues not already explored in the groups discussed above. This is a group from a medium sized town with a rural hinterland. The health issues here were chronic conditions. The health literacy issues were communication and hospital signage. This group reflected particular needs of a rural group. The sense of community here was strong. They provided new aspects to the discussion about health literacy.

Communication: They reported the need for more understanding of how low literacy people hear a message on an answering machine. They reported finding

this a very difficult barrier. This is even more so when a person is already stressed dealing with an emergency of his or her own or that of a relative. General Practitioners (GPs) and locum doctors need to be mindful of this issue. They advise that the message is given slowly and clearly and that key phone numbers are repeated slowly to the caller.

One woman was concerned as to what to do if her child had a serious asthma attack. She had been unaware that there was an asthma clinic available to her and her child in the local hospital. This was despite there being a poster advertising this service in the accident and emergency department. This is a good example of a poster being relied on as the communication tool relaying information.

This is an interesting aspect of health literacy as it invites the hospitals and clinics to think about how they advertise their services to the general public. They also said that the ancillary and administrative staff need customer care training.

In this context the group said they would welcome a demonstration from a health professional as to the management of certain conditions. This was a rural group and there was a lot of reference to Dublin "being a long way off". While geographical distance from services is beyond the remit of this study – the relevance of people not being aware of their local resources is exacerbated by the belief that all is in Dublin.

Informed consent and filling in forms were discussed in this group like others. This can best be summed up in how it makes people feel.

" Filling in forms makes me feel terrible."

"I don't know what I am doing."

" I feel embarrassed when I cannot read or write- there is no privacy for this."

" It is very frightening to have to read a form and sign it."

An issue that has relevance in a rural community was one of privacy regarding people knowing they have difficulty with reading. They would like the doctor or nurse to read through a consent form with them before they sign it. They also need other forms explained to them. In some instances the embarrassment is compounded if the nurse or doctor is a neighbour. What they request is privacy and courtesy in this regard. Once again this underlined the need for health professionals to learn good communication skills.

Hospital signage and medical language was discussed and the following emerged. Haematology – microbiology – words like this are very confusing for the low literacy patients. One of the group members also works in the hospital and regularly had to bring people to these departments as they are unable to find the way themselves. Directional signs also need to be thought through by hospitals.

Looking at literature resulted in the following:

- Regarding medicine they report the need for bigger print on the bottles and brighter letters.
- Make the language plain and simple and to not use shortened abbreviations. The use of pictures would be welcome.
- Similar to other groups they suggested Health Promotion units test the leaflets with the low literacy groups.

The respondents' views about health literacy based on their experiences can be summed up as follows: self esteem; emotional experience of patient with literacy

difficulties; stress to the patient; and the need for understanding and awareness of the health professional of the impact of low literacy on the person.

Finally communication skills training for the health professional is essential to ensuring that communication is improved across the system of health delivery for men, women, children and young people.

It cannot be assumed by a health professional that a patient with literacy difficulties understands instructions or information. It cannot be assumed that silence is consent. Patients who also have literacy difficulties will be more vulnerable than their literate counterpart. They will have little self-esteem to formulate the kinds of questions to engage with the health professional.

Summary

This research has revealed a range of barriers in relation to literacy and health care. These can be grouped under three headings, namely emotional barriers, relational barriers and environmental barriers. These three categories are interconnected.

For example, the research has demonstrated the emotional experiences of patients with literacy difficulties. Their positive experiences speak for themselves. They spoke of being treated professionally by health professionals who greeted them with courtesy and then take the time to read thorough material and ensure they fully understand information.

The opposite experience has been reported when communication has failed. Their self-esteem is low and this combined with the shame of having literacy difficulties and the lack of knowledge that inevitably follows results in a paralysing sense of shame.

Informed consent was an issue in all the respondent groups. It could be argued that informed consent is a core activity that links all the three aspects, emotional, relational and environmental. In short, this means feelings of shame and fear experienced by the patient, poor or difficult communication with the health professional, and finally difficulty navigating in the hospital setting.

Stress is a common response when negotiating one's way to a hospital appointment. Trying to find ones way to a hospital and then to navigate through a myriad of corridors and unrelated departments names could result in patients not making it to their appointments. Training for health professionals is clearly a necessary action that is required to raise the awareness levels about literacy difficulties and to ensure a common standard of communication for all health professionals and ancillary health staff.

Chapter 3

Interviews with Health Professionals

Meetings with

1. Nurse Practitioner
2. General practitioner
3. Health Professionals from One General Hospital
4. Nurse Manager and Staff of Diabetic Day Care Clinic
5. Hospital Doctor - Cardiac Ward

3

Chapter 3:

Interviews with Health Professionals

In total the following health professionals were interviewed:

- Nurse practitioner
- General practitioner
- Out patient nurse manager
- Emergency department nurse manager
- Hospital Pharmacist
- Commercial pharmacist
- National Health Promotion Unit
- Health Promotion Officer
- Hospital Doctor
- Public Health Nurse

1. Meeting with Nurse Practitioner - Medium Size Town

ABOUT THE PATIENT POPULATION

This is a busy practice that works as part of the general medical practice team. Patients with chronic disease and medical conditions are referred to this clinic for treatment and monitoring of their diseased/condition. This includes, asthma, diabetes, cardio vascular disease, cholesterol and women's health. Health promotion is a major part of the work of this nurse practitioner. This clinic also has a role in administering family planning medication and advice.

WHAT INPUT DO YOU HAVE INTO HEALTH PROMOTION?

The nurse practitioner described her role as being primarily about health promotion. It is her practice to read through leaflets with the patient to ensure they have understood it. For example, she uses a pictorial chart to explain asthma management to a patient. This nurse always checks that the patient understands the correct way to administer their medication, which in the case of an asthmatic patient includes masks and inhalers. She also telephones patients when they do not appear for their appointment. This is interesting as low literacy patients can have difficulty with dates and times. It is possible that this practice is ensuring that this group are being included more effectively in their treatment programme by this practice.

AWARENESS OF LOW LITERACY AMONG THE PATIENT POPULATION

This nurse practitioner demonstrated good practice in communicating with her patients. This includes, a time management approach to seeing patients. The first consultation is 30 minutes; follow up initially is every two weeks with a 15 minute consultation. Thereafter, a 15 minute consultation monthly and then subsequently every three to four months.

Even with close contact between appointments and measured timely visits, this nurse admitted she would not have an awareness of low literacy among the patient population visiting her clinic.

It could be argued that her method of imparting knowledge to her patients demonstrates good practice. Her description of how she interacts with her patients is an example of good practice of communication. In this she integrates health information discussions with the health literature.

WHAT LITERATURE DO YOU USE TO EXPLAIN HEALTH ISSUES TO PATIENTS?

Leaflets have a role in explaining health information to patients. She particularly likes leaflets or posters that have pictorial explanations as well as words. This allows her to better explain the reality of an illness better to a patient. She uses both the leaflets supplied by drug companies and the Department of Health and Children, Health Promotion Unit. As already described above, if this nurse practitioner introduces health literature, she talks the patient through this until she is satisfied the patient understands the content. A piece of literature she particularly likes to use is the asthma poster supplied by 3M pharmaceutical companies.

WHAT WOULD MAKE IT DIFFICULT FOR YOU TO EXPLAIN HEALTH ISSUES AND USE HEALTH PROMOTION LITERATURE IN RELATION TO LOW LITERACY PATIENTS?

In the nurse practitioner's experience, the following were important;

- The lack of awareness came out on top. It is clear from this interview that there is good communication practice in this clinic. However, the nurse practitioner, herself admits that she needs to be more aware that a number of her patients may have low literacy difficulties.
- Time management is a necessary skill for health professionals.

To remove these barriers or certainly reduce their impact, she suggested that literacy awareness training be made available for nurse practitioners.

2. Meeting with Senior Partner General Medical practice

This practice has five full time general practitioners; two practice nurses and four full time administrative staff who also manage reception. They provide general medicine to a private and general medical service population. The general medical service population are three thousand in number. There is a larger elderly patient group and a very young population. There are 500 older people over seventy years of age and the young families have a very high number of babies and infants. Both these categories use the service very regularly.

WHAT INPUT DO YOU HAVE IN RELATION TO HEALTH PROMOTION?

The doctor responded that this issue is very complex. For example, when a patient presents himself or herself with one issue, the GP will be on the lookout for other health indicators. This will be based on GPs own specialism of learning. For example, one GP may be knowledgeable about cardio vascular illness, another may be specialised in psychiatric or psychological illness such as depression or alcoholism.

In this instance this doctor has an interest in women's health and the effects of cigarette smoking as well as psychiatric illness. This GP operates in a team and relies on the practice nurses to be involved in the health promotion aspect of the practice.

HOW AWARE ARE YOU OF LOW LITERACY AMONG THE POPULATION?

She admitted to having very little awareness about this issue. This is linked to the time pressure on the GP in this very busy practice. In her surgery she can see up to eight patients per hour. While she claims no awareness she expressed real concern for medicine management with older people.

HOW OFTEN WOULD YOU USE DOCUMENTATION WITH YOUR PATIENTS?

Leaflets are not used very often by the GP. This doctor described the treatment to a patient and where the disease or condition is chronic the patient is referred to the practice nurse. This, as already mentioned, is the team approach to medicine. The practice nurse has more time to interact with the patient concerning education about their disease or condition.

WHAT WOULD MAKE IT DIFFICULT FOR YOU IMPART HEALTH INFORMATION TO THE LOW LITERACY PATIENT?

The General Practitioner listed the following;

- Time is a factor with up to eight patients seen every hour.
- Patients present as either aggressive or passive. The former vent their anger at the doctor. The latter ask little or no questions about their health. The pressure of numbers coupled with the time constraint means that observing a patient with low literacy is almost impossible.
- This GP feels people overuse their GP. This seems to be at the centre of the dilemma for GPs. If they were able to devote more time to their patient initially they may reduce the unnecessary returns by patients to the surgery.
- The queue of patients in the waiting room means it is not always possible to efficiently impart health education. For example this GP cited cigarette smoking, "if I could convince a patient to stop smoking they will almost certainly have improved health and illnesses such as bronchitis , not to mention more serious complications associated with cigarettes".

WHAT SUGGESTIONS DO YOU HAVE FOR IMPROVEMENT?

- Awareness training for GPs at undergraduate and postgraduate levels.
- Target the local study groups of GPs. Most GPs belong to small peer group in order to support their learning. These groups are well attended and this provides a good opportunity to meet and discuss these issues with them.
- It is important to develop a mechanism for medicine management, particularly for older people. Any improvement here would have general application across the low literacy population age profile. For example, medicine dispenser boxes could be made more available.
- There needs to be a balance between involving the patient in their own care and directing them.
- Target college magazines for medical students.
- Target General Medical Services practices with health literacy awareness and progress.

3. Group Interview with Health Professionals from One General Hospital

THE INTERVIEWEES

Present at the meeting: Nurse manager of accident and emergency department; Nurse manager of Out Patient Department; Head of clinical pharmacy; Public health nurse; Nurse tutor; Commercial pharmacy manager; Commercial pharmacy technician.

ABOUT THE HOSPITAL

This is one of the general hospitals that provide hospital services for Dublin. It is located in a low socio economic part of the city and has a large public health patient population. In addition to a large public health population it also has a higher than average patient population drawn from the Travelling Community and in recent times ethnic populations drawn from the refugee and asylum seeking groups also attend this hospital. This group named at 3.1 above have already an awareness of low literacy and are concerned about medication and low literacy populations.

WHAT INPUT DO YOU HAVE INTO HEALTH PROMOTION?

This group expressed a strong desire to ensure that patients primarily take their medication correctly. The knowledge this group has in relation to their patient population is particularly rich in knowing how their patients do or do not manage their medication. They report that in their experience patients tend to swap medicines with one another, seemingly unaware of the potential danger in this.

Overall in this group it was clear that health promotion was something they wished to integrate into caring for their patients. At the conclusion of the meeting it became clear that there already existed models of best practice in the hospital regarding communication and health promotion that could be developed to support low literacy patients in other departments.

One model is carried out in the hospital with all patients in the cardio vascular ward. Here the pharmacist counsels every single patient in this category regarding his or her medication and broader health matters. This is a pilot project. Health literature is used in the pilot project when educating patients about their treatment. The possibility of learning from this project in order to apply the benefits to other areas of communication with patients was discussed at the meeting. It was accepted at the meeting that the problem is not the medication but the communication between the health professional and the patients.

HAVE YOU AN AWARENESS OF LITERACY LEVELS WITH YOUR PATIENTS?

They responded as a group in the affirmative to this question. The issues for this group were not the fact of low literacy but how to overcome it as a barrier to good medical care of the patients.

HOW OFTEN WOULD YOU USE LITERATURE WITH YOUR PATIENTS?

The main pieces of literature include health prescriptions and health promotion literature for chronic complaints.

WHAT WOULD MAKE IT DIFFICULT FOR YOU TO EXPLAIN HEALTH CARE TO LOW LITERACY PATIENTS?

The following are the group's responses to this question:

- Time - it takes a long time to explain medication to patients. This is particularly true of the commercial pharmacy.

- Psychiatric patients need particular care and attention and time impacts here also.
- Multiple prescriptions create complexity.
- Patients are asked to wait in queues and this makes demands on their patience and willingness to listen.
- People are fearful of interacting with the health professional.
- Patients will never tell a doctor they cannot read- the research in this study reveals that they may tell a nurse.
- Patients are unable to read letters and prescriptions.
- Low self esteem of patients.

WHAT SUGGESTIONS DO YOU HAVE FOR IMPROVEMENT?

The following points were made by the health professionals:

- The health professional must constantly reinforce the knowledge the patient has already about their condition- this is something the hospital out patient nurses engage in a lot of the time.
- Create the possibility for health education sessions with low literacy patients.
- Provide communication skills training courses for health care professionals. This could be designed and developed in conjunction with the local VEC adult literacy service.

The discussion concluded that the best approach to this problem was to look at models of good communication that are already happening in the hospital. Learn from these models and replicate them in other parts of the hospital.

4. Interviews with Nurse Manager and Staff of a Diabetic Day Care Clinic

ABOUT THE CLINIC

This Dublin clinic provides ongoing care and monitoring of patients with diabetes. They have 3,500 patients. They explained that there are two kinds of diabetes, Type 1 and Type 2. They are quite distinct diseases and require different kinds of treatment. The treatment can vary from diet management to insulin injections. Thus this disease has to involve the patient and health care professional in a close relationship to ensure the best possible outcome for the patient.

It was reported by the nurse manager that data is showing as alarming increase in the numbers of people suffering from Type 2 diabetes.

WHAT INPUT DO YOU HAVE INTO HEALTH PROMOTION?

The key part of the clinic's work is health promotion and education. Over time the staff have developed good teaching skills. This allows them to discern the level of knowledge and understanding the patient has about their disease. It also ensures the staff impart the relevant knowledge to the individual patients. One of the important medical facts is that all Type 2 patients are clear about the importance of their diet as cardio vascular disease can develop if this is not carefully managed.

HAVE YOU OR YOUR STAFF AWARENESS ABOUT LOW LITERACY LEVELS WITH YOUR PATIENTS?

The nurse manager and her staff admitted they had no knowledge or awareness

about this issue. Type 2 tends to affect older people and is linked to lifestyle, such as diet and body weight. Considering the number of patients assigned to this clinic anywhere between one quarter and a half may have literacy difficulties that will have implications for their understanding of their health care.

HOW OFTEN WOULD YOU USE DOCUMENTATION WITH YOUR PATIENTS?

The answer to this was quite often with the pharmaceutical company supplying most educational material. This is explained by the fact that clinics do not have their own budget to produce their own educational material.

The booklets they tend to use are colourful and attractive publications. They all use plain English instead of medical terminology. The staff find these booklets useful when discussing treatment with their patients. They also use a short diet leaflet, which they make themselves. These documents use large print and pictures. Information is imparted to patients by meeting them regularly. Patients in this clinic get to know the staff well. The nurse manager has been in this clinic for sixteen years and as such has accompanied many patients on the journey through this illness.

WHAT MAKES IT DIFFICULT FOR YOU TO EXPLAIN HEALTH CARE TO LOW LITERACY PATIENTS?

The main factors cited by the respondents are as follows;

- The physical space allotted to the clinic is small. All the work is carried out in one room. This means that it is the norm that two consultations are conducted in this room at the same time. This has implications for privacy in making it safe for patients to disclose they have a reading difficulty.
- There is a constant throughput of people from other hospital departments to this clinic. The phones are constantly ringing, which adds to the difficulties for a low literacy patient and their health professional.
- Lack of awareness of the topic is a factor.

WHAT SUGGESTIONS DO YOU HAVE FOR IMPROVEMENT?

One practice that is proving very successful in this clinic's work with their patients is the development of an information group. This has proved successful with the patients who attend this group. The beneficial outcomes of this method of support and health promotion are:

- Increase in confidence levels of the patients not only in relation to their illness but also in relation to their overall social confidence.
- They have much clearer knowledge in the management of their illness.
- The patients have developed a support system from one another.
- Their level of dependency on the clinic is reduced.

5. Interview with Hospital Doctor – Cardiac Ward

This ward sees about fifty people daily. Cardiac disease is one of the biggest diseases affecting the population. For this reason patient turnover is managed very closely.

WHAT INPUT DO YOU HAVE INTO HEALTH PROMOTION?

The treatment in this ward is mainly acute. People are already quite ill when they

arrive here and need medical intervention. Patients present here with a range of illnesses in addition to the health disease such as diabetes. Attempts are made to influence the patient to take part in their own care and to see the value of making life style changes.

WHAT AWARENESS HAVE YOU OF LOW LITERACY?

This doctor is from Australia where awareness of difference and disability is high. She reports that she herself has a high awareness of this issue. She never assumes that a patient can read. She noticed this first when working in children's medicine when Traveller women would bring a child with them to speak on their behalf to the doctor or nurse.

HOW OFTEN WOULD YOU USE DOCUMENTATION WITH YOUR PATIENTS?

This doctor reported using a whole range of medical administrative documents from prescriptions, medical certificates, social welfare forms, medicine information, life style leaflets and booklets. She also referred to consent forms. It is her practice to read through the consent forms with ALL her patients.

"I never assume a patient is literate".

WHAT MAKES IT DIFFICULT FOR YOU TO EXPLAIN HEALTH CARE MATTERS TO PATIENTS?

Time pressure is a real factor here. In general she finds that patients with cardiac disease are not open to health education. This, she feels, is a cultural barrier of its own. It is a minority of patients that take the advice and make the necessary changes to their life style.

WHAT SUGGESTIONS DO YOU HAVE FOR IMPROVEMENTS?

Health promotion regarding heart disease needs to begin much sooner in a person's life. In her experience patients just want a drug to 'fix' the problem. In her opinion health promotion at national level is too timid. She has strong memories of health promotion songs from her childhood that have influenced behaviour strongly and in an attractive way.

Summary

- Awareness training is essential for health professionals and health promoters.
- This is an issue that can be solved through good communication not more medicine.
- The use of pictorial material is an effective tool in communication.
- Training in communication skills to maximise the interaction between health professionals and low literacy patient.
- Develop a dialogue between the health professionals and the patients with literacy difficulties to develop the possible solutions raised by the health professionals.
- Learn from international experiences of health promotion such as that described by the Australian Doctor.

Chapter 4

Conclusions

1. Communications and Patient Perspective
2. Communications and the Health Professional's Perspective

4

Chapter 4: Conclusions

Equality Centeredness:

Quality:

Accountability.

“The need for and opportunities for multi-sectoral partnership working have never been greater”

National Health Strategy (2001)

The conclusions are discussed under the following headings:

Communication and the Patient Perspective

Communication and the Health Professional’s Perspective

Summary of conclusions

1. Communications and the Patient Perspective

It is generally accepted that patients from all levels of the literacy scale are stressed when meeting their health professional. The vulnerability associated with one’s health problems is common to most people. However, the added difficulty for those members of the population with literacy difficulties creates a whole range of problems in addition to the presenting health matter.

The patient groups consistently reported the following issues as being pertinent to their health literacy experiences:

- a) Low confidence and low self esteem of patients.
- b) The difficulty in giving informed consent.
- c) Embarrassment and low self esteem of young people.
- d) Lack or absence of knowledge about other health services
- e) Use of print media/ wide variety of standards
- f) Poorly presented hospital signage
- g) The need to build on good practice

a) LOW CONFIDENCE of patients in discussing their needs with the their health professional was raised in all group meetings. This would be related to low self esteem, where people do not have the confidence to ask for information to be repeated or for information to be further clarified. An example of this was when one mother described managing her infant daughter’s asthma attacks. The group process allowed the emergence of this woman’s history with this illness. She had in fact lost a member of her family to asthma. This, plus her literacy difficulties, compounded to make it very difficult for her to access the necessary information to learn about managing this disease.

In another group a woman was visibly upset in telling her story. She still had no knowledge of what the surgeon had removed from her as she had not understood the information given to her. This has implications for the giving of informed consent. Her inability to understand the literature put before her was compounded by her low self-esteem. This lack of knowledge had impacted on her recovery.

The impact on the respondent's self esteem is clear from the continuous use of words like 'embarrassment', 'feeling terrible' when asked to write one's name and being 'very frightened' when asked to read and sign a form. All these are experiences prior to interaction with the health professional.

Research in this report demonstrates that patients with literacy difficulties have particular issues with low self-esteem. The research also shows that this impacts on the quality of the interaction between them and their health professional. In other words this could be seen as a power imbalance between the health professional and the patient with literacy difficulties. Rollinck et al explains:

'The origins of passivity do not lie only in the patients, but also in the way they are spoken to and dealt with by practitioners.'

This is a confirmation of the need to develop awareness and communication skills in the health professionals.

- b) INFORMED CONSENT** is a topic mentioned by patient groups. One mother described discovering her daughter had her appendix removed after her daughter had undergone surgery for another complaint. This mother discovered this new knowledge in what she perceived as a casual conversation with the nurse. Where a patient is showing signs of resistance when requested to sign a document, it may be an indication this person has literacy difficulties. Explaining the consent form is essential to encouraging the patient to engage in his or her own treatment.
- c) EMBARRASSMENT AND LOW SELF ESTEEM OF YOUNG PEOPLE.** The groups specifically devoted to young people demonstrated that their bravado displayed at the outset of their meeting was indeed just skin deep. When they engaged in the process and the discussion it became clear that they feel very outside the health care system. It was clear from the research that they need to be engaged in the area of sexual health, drugs and alcohol. Literature needs to be designed with this age group in mind. While the adult groups responded well to literature with the picture of a baby on the front, this group would also respond to pictures of themselves on the front of the literature. Again the process of engaging with the young person and using literature as a talking and learning point would, it is felt, be an effective way of improving their experience of health literacy.
- d) LACK OF KNOWLEDGE OF OTHER HEALTH SERVICES.** This was particularly true of the groups outside Dublin. What the Dublin groups had in common was access to a range of children's hospitals and general hospitals. In the case of young Dublin mothers, they had access to a range of family planning and women's health care centres in the form of public and voluntary sector clinics.

Rural groups reported the feeling that all services were in Dublin. What transpired in the group meeting was that some group members had been unaware of the presence of key medical services in their locality. The low self esteem and associated stress experienced by one particular group member was evident in the meeting. There is a possibility of creating support groups where people can meet to discuss their health issue in a safe and supportive environment.
- e) USE OF PRINT MEDIA.** There is a wide variety of print media available in health care settings and a heavy reliance on the written word. Adults in this research tended to take leaflets and booklets:

- when it is discussed in conjunction with a health professional
- where they can relate the literature to their condition
- where the medical term is used, it is accompanied by the plain English word e.g. **optical – eyes**
- where plain English is used and not medical terms only
- where the visual image on the cover attracts them.

The support group managed by the Diabetic clinic in Beaumont hospital is a good example of an initiative that is contributing to positive health promotion. This type of venue could include video material. Video material is useful in creating a discussion group that could include literate and low literate patients.

- f) **HOSPITAL SIGNAGE.** The use of medical language in signs is off putting. One member of the group was herself an employee of a hospital. She reported having to often help people find their way around the hospital. She is literacy aware having come through the adult literacy scheme. One suggestion mentioned was the use of colour coding. This could help identify access to hospital departments and clinics.
- g) **BUILDING ON GOOD PRACTISE.** Patients have reported good experiences in relation to health literacy. One mother described her good experience regarding her child's treatment for asthma. This was in contrast to the mother who reported a difficult experience. A practice nurse treated this mother and her child. There was good communication, respectful behaviour towards the child and the mother, reading the literature together and the use of pictures to reinforce information. Now this mother and child are more confident about managing the asthma condition. This has a knock on effect of reducing stress from the mother, which will have benefits for the child.

Parents reported consistently good experiences in children's hospitals. This included sympathetic treatment of young mothers and infants, short queuing time, discussions with the parents about their children's conditions and literature they could share with their children.

2. Communication and the Health Professional's Perspective

- a) Lack of awareness
- b) Time pressure
- c) Informed consent
- d) Low self esteem of patients. Patient stressed during consultation – do not offer information or ask questions
- e) Models of good practice.

- a) **LACK OF AWARENESS.** The honesty with which the health professionals revealed their lack of awareness in relation to the literacy skills of their patients was refreshing as it allowed very good discussion to take place with the researcher.

The idea that 25% of their patients may be struggling in this way was an eye opener for them. An action to come from this study would be an awareness

campaign targeting key groups of stakeholders to raise awareness on this topic. The general practitioner interviewed in this report suggested that information articles be published in newsletters and publications, targeted at student and qualified doctors. She also suggested the targeting of the general practitioner study groups. These study groups number eight persons. This may seem a small number, however when one takes into account the number of patients in a general practice, it is possible to see the potential. In this instance, this general practice has at least 3,000 medical card patients of whom at least 700 may have literacy difficulties.

It has to be said that the lack of awareness does not automatically lead to the conclusion that health professionals do not communicate well with their patients. In many cases it was clear that models of good practice were occurring despite the lack of awareness about low literacy skills.

The implementation of a literacy awareness training programme would ensure that these good models of communication would be even more effective.

Conclusion

Literacy awareness training for health professionals is essential to ensure there is:

- a) good communication with patients
- b) a better understanding of difficulties faced by individuals with low literacy skills.

b) TIME PRESSURE

This was particularly true of the doctors. They have to see patients quickly as their skills are primarily to diagnose and monitor the patient's progress. This means that the development of the relationship with the patient is often managed by the nurse.

However, if doctors are aware that at least 25% of their patients may have difficulty in relation to literacy, they may have an increased understanding of a patient's resistance to certain treatment. The inability to understand a medication regime becomes much easier to understand if the doctor has an idea the patient may have a literacy difficulty.

Nurses in clinics report good systems when dealing with patients. They allot certain time for their patients. In the case of the practise nurse in a general practice, she was aware the doctors were under severe time pressure to see patients. She however was able to allot 30 minutes for the first consultation and reduced amounts of time thereafter as the patients become more familiar with their treatment and monitoring of a condition.

The benefits of awareness and good communication practice need to be revisited by health teams. Where the nurse is the long-term educator of the patient, this needs to be fully supported by the consultant.

Conclusion:

While time pressure in the health services is visible for all to see, the benefits of taking time in certain instances cannot be underestimated. One area where patients need time is when they are being asked to sign a consent to treatment form. There are real benefits to the patient with low literacy skills if this is performed with care.

c) INFORMED CONSENT

Where the doctor is interacting with a patient with low literacy skills, they will need to take greater care to ensure they fully understand their proposed treatment. The patient groups have reported incidents of not being in a position to give informed consent. The impact of this on their emotional well-being has also been noted. It takes skill and understanding on the part of the doctor to understand this and ensure the patient fully understands their condition and the treatment being proposed.

d) LOW SELF ESTEEM OF PATIENTS

One group of health professionals were aware of the particular difficulties being experienced by members of the travelling community in relation to literacy. They were less clear about the impact this was having on the settled community. They were aware of the impact of low self-esteem of patients. This low self-esteem was reflected in the way the patient viewed himself or herself in relation to their illness. Health professionals often view this as the patients lack of interest concerning their personal health. One example was patients who swap medicine with one another without any understanding of the inherent danger of this practice.

Some health professionals also reported being aware that patients are stressed when meeting their health professional. This combined with the vulnerability anyone feels regarding his or her health is exaggerated more when one also has a literacy difficulty.

“They won’t tell a doctor they cannot read”.

Conclusion

Health professionals, in addition to being aware of the effects of low literacy patients’ cognitive capacities also need to understand the emotional content of this lack of skill. Training is again recommended here to increase awareness and understanding for the health professionals.

The use of teamwork needs to be considered as a solution to supporting doctors’ explanations of the complexity of health education and disease management. There already exists the model of the nurse taking on the longer-term part of the relationship. It may be possible to factor this into the overall communication with the patient.

e) MODELS OF GOOD PRACTICE

In the interview with health professionals it is fair to say that there are models of good communication practice emerging. When combined with health literacy awareness this could be the basis for an improvement in this area of health literacy.

The practice nurse working in a busy general practice demonstrated good practice on several levels. She was in a position to set up the time management for the appointment system with her patients. This allowed for the patient to engage at a more leisurely pace in relation to their disease or condition. The relationship between the practice nurse and the patient has an opportunity to establish. Given that she now has a greater awareness about health literacy it is possible she will be in a better position to be more supportive.

In this instance there is evidence of good practice in using the available

literature. She combined text and visual material and comprehensively read through the material with the patient.

Another example of good practice was a pilot scheme in a hospital setting. In this instance patients with a particular heart condition were to receive individual counselling about their disease and medication. The learning from this scheme will be studied to see if there is transferability to other areas of medicine.

A third example of good practice is in a clinic setting. Here the nurse manager has established an information group for patients. The purpose of this group is to help the patient become more informed about their illness and so manage their health better. Since this group has begun, the nurse manager has noticed an increase in the patients' self-confidence. They are more supportive of one another and are consulting medical staff which shows they are learning to positively manage their illness.

Conclusion:

There is no need to reinvent the wheel. It is important to identify models of good practice that are already occurring in the system and to develop these.

Summary of Conclusions from this Study

- 1) Provide meaningful awareness raising sessions in a targeted way to the key personnel.
- 2) Develop models of good communication practice relevant to the patient's needs and illness. For example, a support group for diabetics, which is a long-term illness.
- 3) Recognise that people with literacy difficulties have low self-esteem.
- 4) Treat all patients the same in relation to information. This is about creating common standards of communication. In this, communication is both a health issue and issue of quality of standards of delivery.
- 5) Low literacy is a base line for the delivery of good health care. If patients with low literacy skill feel they are being understood and supported by their health professional, it will have an affect on health communication for all patients.
- 6) Be mindful when leaving a telephone answering machine message.
- 7) Follow the NALA Plain Language guidelines when making material for the general public.
- 8) Health professionals should read written health material with patients.
- 9) Ensure that health promotion programmes are culturally sensitive. The most effective means of ensuring this is to allocate Traveller organisations and other ethnic minorities a central role in both the design and delivery services.



Chapter 5

Health Literacy Policies and Strategies

1. Research
2. Budget
3. Local Networks
4. Accessibility
5. Co-ordinating body for health literacy
6. Training
7. New ways to communicate

5

Chapter 5:

Health Literacy Policies and Strategies

Introduction

The purpose of this research project was to explore the issue of health literacy among Irish adult literacy learners and health practitioners and produce policy oriented research.

A total of 78 adults with weak literacy skills were asked about their experiences and possible solutions. These 78 adults are representative of the groups targeted by the National Strategy for Health Promotion.

In order to develop a strategy it is important to see the problem in a context. Some 25% of the population scored at Level 1. A further 30% managed to get to Level 2, with Level 3 regarded as the minimum level needed in today's Irish society. This means that over 50% of the population may have some difficulty in relation to health literacy. All the literature in this study is in agreement that health literacy is a complex problem that requires a range of responses. This means that all those engaged in the delivery of health care, should be involved in delivering the solution.

Health Promotion Managers and their staff are uniquely positioned to respond to this problem as they have specific responsibility for the co-ordination of and dissemination of health promotion campaigns. Those engaged in administration need to be made aware of the impact of issues such as hospital front desk services, switchboard standards and the ease with which patients can navigate to their hospital department.

Medical /clinical staff have the onerous responsibility of ensuring that the patient is fully informed of their condition and the recommended treatment.

This report has highlighted a number of issues which could be translated into policy by the Department of Health and Children.

1. Research

According to the Government's Strategy for Health Research (2001)

"Within the health services there is great potential for strong institutional research strategies building on patient and client involvement"

There is a critical need for additional Irish research into health literacy. With the publication of the above named strategy in 2001 now is a good time to put literacy on the national research agenda. The establishment of a research and development function in the health services will involve new structures. Each health board will appoint Research and Development Officers in health boards. Each health board/authority will have to specify how they intend to develop links with the voluntary sector among others as part of their Research and Development strategies.

ACTIONS

1. Health literacy should be explored by each health board.
2. Literacy should be explored in the proposed review of paediatric services outlined in the new health plan.
3. Irish research needs to be commissioned in areas of literacy training, communication, effects of low literacy skills on chronic illness etc
4. A specific literacy research fund should be available to health and literacy practitioners, who should be obliged to publicise findings.

2. Budget

Health care professionals need money allocated to literacy friendly health material, pay for literacy awareness training sessions and plain language editing. Currently there is no budget for these initiatives.

ACTIONS

1. There should be a health literacy budget which is accessible to health and literacy practitioners to develop a health curriculum.
2. This budget should be guaranteed each year and based on long term projects which can be mainstreamed.

3. Local networks

This study found that health practitioners were not aware of their local VEC run literacy scheme. We know that literacy schemes are great vehicles for accessing “hard to reach” health clients. We also know from international research that when “health literacy” classes are taught by literacy and health education teachers in a variety of community settings, they attract groups of learners who often do not avail of their local literacy service.

Locally there is the great opportunity to inform people and open up a forum for debates on how the Irish health care system works. According to the new Health Strategy there will be a strong focus on providing care in the community. Numerous proposals are made including the strengthening of integration between primary care and specialist services in the community. A number of difficulties need to be overcome if the potential between health and community literacy practitioners is to become a reality.

ACTIONS

1. Design local programmes that involve partnership between literacy practitioners and health practitioners. Rima Rudd (2002) points out that adult educators are more likely to adopt materials developed by experts in their field. Likewise health practitioners are more apt to attend to and approve of processes and materials developed by health practitioners and involve literacy learners.
2. A publicity campaign should be organised to introduce the VEC local literacy to health practitioners. Health care settings could refer patients to their local literacy scheme.
3. Encourage the use of peer educators. They have proved particularly successful in the USA as they are very credible. NALA train adult literacy learners to be involved in NALA’s Literacy Awareness Training days.

4. Accessibility

The Department of Health's Health Promotion Unit is committed to ensuring that health promotion information is accessible to all those categories named in the National Strategy for Health Promotion 2002 – 2005. According to the new Health Strategy there is a need for a strategic change around how the health system is experienced by the public. Literacy learners are part of that public and the following actions would make an impact.

ACTIONS

1. All health promotion literature should be subject to literacy proofing. The overall responsibility and co-ordination of this initiative should rest with the Health Promotion Unit.
2. The level of literacy skills demanded of patients in all health care settings must be modified.
3. All front line staff in hospitals and health centres should be literacy aware and be able to verbally convey information.
4. A national publicity advertising campaign should be developed to reach out to people experiencing literacy difficulties who might be delaying treatment.
5. Each hospital could have an education room which would contain information about health issues and services. Staff working in these should be trained as literacy tutors and act as a referral to the local VEC literacy scheme.
6. In 1998 the Clinton Administration mandated federal agencies to use plain language in their dealings with the public. Department of Health and Children could initiate a similar policy. Public hospitals could be used with a pilot project.
7. NALA should use their experience in producing materials to develop health information packs and brochures which literacy practitioners could use in VEC literacy schemes.

5. Co-ordinating body for health literacy

This research shows that there are isolated, project based initiatives taking place in different health settings. Individuals in hospital departments are making efforts to tackle this issue, with no guidance from management. These isolated efforts, while worthwhile are not integrated into mainstream department activities. A national programme is needed to co-ordinate work between health policy makers, literacy practitioners and health support groups ie multisectoral approach.

This research also found that health practitioners are struggling to keep up with material they receive each day from different health advocacy groups. A new model of communication needs to be established so that health information can be more effectively disseminated.

ACTIONS

1. A national Health Literacy Board should be established which would provide a co-ordinated support structure. This board could report to the

proposed Research and Development Officer in the Department of Health and Children whose role is to provide central leadership on health research policy.

2. This Board would be funded by and report to the Department of Health and Children.
3. The Board will be responsible for researching health literacy in different health settings in line with international best practice.
4. It would be responsible for working with a multiplicity of providers and promoting local initiatives to other potential beneficiaries. It would create a dialogue between those engaged in health promotion and the patient with literacy difficulties.
5. It is recommended that a link be made to the Research and Development Units, due to be established in each Health Board area.

6. Training

Training needs to be provided for health administrators, health professionals and those involved in health promotion. The aim of this training is to raise awareness and develop skills for the active development of a health literacy culture. The Health Strategy 2002 stresses the need for a qualified, competent workforce to meet the demands of the health system. Each Health Board should be responsible for the training need highlighted by this research. (See Appendix E for draft training strategy)

ACTIONS

1. The Health Promotion Units within each Health Board could implement training for health professionals and Health Promotion Officers.
2. A representative group from the policy category (The Department of Health and Children) and the operational/clinical category (The Health Promotion Unit staff and health professionals) should be included in a pilot training awareness programme. The outcomes from these groups can then be studied with a view to mainstreaming the learning.
3. Health boards could work with NALA to accredit this training.

7. New ways to communicate

It is vital to see communication as a core activity of the health professional and as such it needs to be clearly acknowledged as an essential skill in the delivery of quality health care.

Listening to one's patient is key to building and developing the services and information systems that will support those with low literacy difficulties. This is the core of service culture, which puts the client, or in this case the patient, at the centre. The real needs of the patient need to drive the way in which health information is imparted.

Patients with low literacy experience real difficulties in dealing with such things as prescriptions, appointment cards, health promotion literature and consent forms. This can only be improved if those professionally responsible for the delivery of services also take note to look at their own communication systems at the

organisation level, the interdepartmental level and finally between the health professionals and the patient

Dr Rima Rudd (2002) best sums up the direction of this work:

“Professionals in public health and health care do not have the skills or mechanisms to improve the literacy skills of their community population or of their patients. They can, however, work to improve their own communication skills, the procedures followed for communicating with and interacting with people, and the forms and materials they write.”

ACTIONS

1. The education of health professionals at undergraduate level needs to include an understanding of health literacy.
2. Different methods of imparting information other than text should be actively explored.
3. Professional jargon in forms, signs and health education material must be modified.
4. All health literacy pilot programmes need to be co-ordinated and monitored so as to allow the learning to become part of the normal management of communication.
5. The development of an information pack by NALA would benefit many health practitioners to begin to develop greater understanding and effectiveness when presenting information in all its forms to the low literacy patient.

Appendices

Appendix A: OECD International Adult Literacy Survey (IALS) 1997

Appendix B: Model for cultural change

Appendix C: Submission by National Adult Literacy Agency to the National Anti Poverty Strategy Working Group on Health March 2001.

Appendix D: Check list for easy to read materials - Source: Maine AHEC Health Literacy Centre.

Appendix E: Draft Health Literacy Training Plan

Appendix F: Glossary of Terms

Bibliography

Appendix A

OECD International Adult Literacy Survey (IALS) 1997

LITERACY LEVELS

LEVEL 1:

Indicates very low literacy skills, where the individual may, for example, have difficulty identifying the correct amount of medicine to give to a child from the information found on the package.

LEVEL 2:

Respondents can deal only with material that is simple, clearly laid out and in which the tasks involved are not too complex

LEVEL 3:

Respondents can identify several pieces of information located in different areas and also integrate, compare and contrast.

This level is considered as the minimums desire able threshold in many countries but some occupations require higher skill.

LEVELS 4 AND 5:

Are reported as a single category and involved literacy tasks that require the ability to integrate several sources of information or solve more complex problems

Appendix B

Models for cultural change

- STEP 1** Identify the Power people/individuals
Identify the Power groups
Identify the decision makers
Identify the decision influencers

- STEP 2** Understand the structure

- STEP 3** Identify the 'powerless groups'

- STEP 4** Develop the 'powerless groups'
Develop the powerful groups

- STEP 5** Create a leadership environment

- STEP 6** Encourage a sense of responsibility

- STEP 7** Encourage a questioning of the existing structures/systems by the power groups (the powerless already know the difficulties).

- STEP 8** Create a space for dialogue between the powerful and the powerless groups.

Adapt report, 1997, Anne McCarthy

Appendix C

Submission by National Adult Literacy Agency to the National Anti Poverty Strategy Working Group on Health March 2001.

BUDGET

Health literacy is a problem without a budget. Without a budget and a strategic plan it is impossible to consistently tackle this complicated issue. It is a health problem which reaches across age groups and this means that there should be different budgets for each particular group.

ESTABLISH A SPECIFIC FUND FOR LITERACY PRACTITIONERS

Adults consider health a personal matter and not an educational matter. If health was introduced as a subject into literacy schemes it is an ideal subject to encourage participatory adult teaching methods

HEALTH PROFESSIONALS NEED LITERACY AWARENESS TRAINING (LAT)

One of NALA's most important objectives is to raise public awareness about the nature of the literacy problem among adults in Ireland.

Our LAT programme supports workers to respond more appropriately to clients with reading and writing difficulties. This one-day workshop gives participants the opportunity to explore the causes and effects of literacy difficulties and to identify how best they can respond. When participants evaluated this training they pointed to a heightened awareness of literacy issues and concrete proposals for changes in their work practices

INTEGRATING LITERACY TRAINING INTO MEDICAL TRAINING

Training programmes require the acquisition of specific work related and personal skills. Many individuals may not possess the required literacy level to achieve successful completion or transfer of learning from the training. Many programmes have sought to address this by providing dedicated literacy tuition to enable the individual to improve literacy skills. We believe that alongside specific literacy provision, literacy skills should be integrated with the vocational (or other) training. To be effective however, the trainers will need to ensure that the development of the literacy skills is an explicit part of their programme at all stages. This involves a planned and purposeful approach.

USE APPROPRIATE LANGUAGE - PLAIN LANGUAGE

Few people are offended by "literacy friendly" reading material that is well designed. Everyone wants information that is easy to read and understand.

NALA has acquired expertise in this area and would like to see the use of plain language incorporated in all health care training.

NALA has always campaigned for all bodies writing for the public to take into account individuals running into trouble with everyday reading and writing material.

WORK WITH HEALTH PROFESSIONALS TO DEVELOP CURRICULUM

We would also welcome developing a health and literacy curriculum, which could be developed by health promoters in partnership with literacy practitioners. Literacy schemes are great vehicles for accessing “hard to reach” health clients.

MAKE HOSPITALS LITERACY FRIENDLY ENVIRONMENTS

Lowering the reading levels of documents is one step, but there are other steps the health service can take to make their environment easier to navigate. In Canada for example signs are being used in hospitals as against words. A good analogy would be international road signs and signs used in airports. Areas in hospitals could also be colour coded. Photograph based materials are also very effective.

ESTABLISH NATIONAL HEALTH LITERACY RESEARCH BOARD

There is a serious literacy research deficit in Ireland. We have to rely on international research when writing health policy documents.

- Develop methods for measuring health literacy in Ireland.
- Explore which areas people are running into trouble encountering the health service.
- Explore how low literacy skills impact on adults parenting skills.
- Carry out national survey among adult literacy students documenting their experiences of the health care system.

PUBLICITY ADVERTISING CAMPAIGN

Society needs to change its attitudes about literacy. There is still a very big stigma to having a literacy difficulty and this means that it can be a silent disability. A national television campaign is needed to explain to the public that the system can accommodate them. This would reach out to those experiencing literacy difficulties and introduce them to the appropriate support available for low literacy. People need to be told that it is not their fault they have weak literacy skills but it is a good idea to bring it to the attention of the health worker. People could be told that their local health worker is prepared for this information and will work with the person to make sure that it does not interfere with their health treatment.

We know from talking to adult learners that television is the best option as a publicity tool. It is the most accessible and the best medium to explain a sensitive issue such as this. When NALA has engaged in TV advertising it has always resulted in a large increase in adults joining the literacy service.

PRIORITISE THOSE IN MOST NEED

Efforts to combat poor literacy skills could start with those most in need of literacy friendly information and navigating the health care system. The Irish results of the IALS showed that a significantly higher proportion of adults in the older age group scored at the bottom literacy level. A research project should be established to quantify how much older people are experiencing problems with the health service, through weak literacy skills.

Appendix D

Check list for easy to read materials – Source: Maine AHEC Health Literacy Centre.

ORGANISATION:

The cover or title page indicates the core content and the intended audience.

Action steps or desired behaviours are immediately evident.

Major points are limited overall, as in any section or page of a longer document. Information is organised and presented from a users perspective: i.e, it is 'chunked' and sequenced in a way logical to the intended users.

Headers and summaries aid organisation and provide message repetition

WRITING STYLE

Writing style uses active – voice, conversational style, vivid nouns and verbs, pronouns, friendly tone.

There is little or no technical jargon, and where necessary, it is explained.

Words and sentences are short – but not to the point of being 'choppy'. Readability is reasonable for the audience intended.

Bullets are used for lists.

APPEARANCE: TEXT/ PRINT

The pages and /or sections look uncluttered. There is ample white space, generous margins, and no more than five inches of type running horizontally across the page.

The print is at least 12 to 14 point with a serif. Clean, simple letter styles are used. Maximum of 2 or 3 diverse styles on a page.

Lower case letters (not all capitals) are used throughout. Emphasis is achieved with boxes, lines, bolding different typefaces or increased print size as appropriate.

ILLUSTRATION

Illustrations are used to attract attention and re-emphasise the text.

Illustrations are simple, without unnecessary clutter, and fit the intended audience.

APPEAL

The piece is culturally and age appropriate.

The piece matches as closely as possible the logic, language and experience of the intended audience.

The material engages the readers, perhaps by using a dialogue or story format or testimonials, perhaps by inviting interaction (e.g. with questions or actions to take).

Appendix E

Draft Health Literacy Training Plan

Aim of training:

- To raise awareness among a representative group of health care providers and health promotion staff
- To create a clear understanding of the quality of communication required to meet the needs of patients with literacy difficulties
- To learn new communication skills.

Like the NALA Literacy Awareness Training learners would also be involved in this training.

Issues explored would include:

- Extent of literacy in Ireland and comparisons with international countries
- What are the causes of low literacy skills
- Reality behind the literacy statistics
- How low literacy skills impact on a person's health care
- How plain language can make a difference
- Why is there a heavy reliance on the written word in health care
- Explore strategies for building rapport and collaborating with patients.
- How to assess material- role of Readability tests.

Appendix F

Glossary of Terms

ABE – Adult Basic Education - refers to the development of competence in adult skills that are need to full take part in society such as literacy numeracy, communications,

ADM - Area Development Management – a statutory organisation set up by the Department of An Taoiseach which funds and oversees local development projects

AEOA - Adult Education Organisers Association

ALO - Adult Literacy Organiser

Breastcheck – responsible for the National Breast Screening Programme that aims to reduce breast cancer related deaths in women

Dental Health Foundation Ireland – Government funded organisations promoting better dental health

DES – Department of Education & Science

FSAI - Food Safety Authority of Ireland – statutory body establish top over see the improvement of food safety

Health Boards – established under the Health Act 1970 for the administration of the health services in the State. There are currently 10 health boards established in Ireland.

Health system – term used to describe agencies that provide health services or whose actions have an impact on health

HRB – Health Research Board – provides advice on health research and related matters.

IALS - International Adult Literacy Survey

ICCPE - Irish Centre for Continuing Pharmaceutical Education

Library Council – Organisations for the development of libraries

Literacy Implementation Group – committee established to oversee the implementation of the adult programmes of the White Paper

NAPS - National Anti-Poverty Strategy – government medium term plan to tackle poverty

NDP – National Development Plan 2000-2006- government medium term plan for economic and social development

Out-patient - A patient who attends a hospital clinic for treatment and is not admitted to the hospital.

OECD - Organisation for Economic Co-operation and Development

VEC - Vocational Education Committees – managing adult and further education

VTOS - Vocational Training Opportunities Scheme

Western Health Board – public health services operation and management organisation for the western region

White Paper - Government policy document outlining the plan for the future of adult education

Youthreach – refers to local training units, in different centres around Ireland, providing vocational and basic skills to early school leavers under 18 years of age

Bibliography

Davis, T., Crouch, M., Wills, G., & Miller, S. (1991). "Rapid assessment of literacy levels of adult primary care patients." *Family Medicine*, 23 (6), 433-435.

Department of Education and Science (1997) *International Adult Literacy Survey: Results for Ireland*. Stationery Office, Dublin.

Department of Health and Children (2001) *Making Knowledge Work for Health a Strategy for Health Research*, Dublin Stationery Office.

Department of Health and Children, (2000) *National Health Promotion Strategy 2000- 2005*, Dublin Stationery Office.

Department of Health and Children (2001) *New Health Strategy*, Dublin Stationery Office

Department of Health and Children (2001) *Primary Care: A New Direction*, Dublin Stationery Office.

Department of Health and Children (1994) *Shaping a Healthier Future- A strategy for effective health care in the 1990s*, Dublin Stationery Office.

Department of Health and Children (2002) *Traveller Health, a National Strategy, 2002 – 2005*

Department of Social Community and Family Affairs (1997) *National Anti-poverty Strategy- Sharing in progress*, Dublin Stationery Office.

Doak CC., Doak LG., Root JH.(1995) *Teaching Patients with low literacy skills* 2nd edition Philadelphia, Pa: JB Lippincott.

Friel S., Nic Gabhainn S. and Kelleher C. (1999) *The National Health and Lifestyle Surveys:survey of lifestyle attitudes and nutrition and the Irish health behaviour in school-aged children (SLAN and HBSC) Galway: Centre for Health Promotion Studies; National University of Galway.*

Green, L & Kreuter, M (1999) . *Health Promotion Planning: An Educational and Ecological Approach*. 3rd Edition. Mountain View, CA: Mayfield Publishing Company.

Hohn, Drew, Marcia., (1996-1997). *Empowerment Health Education in Adult Literacy: A guide to public health and Adult Literacy Practitioners, Policy Makers and Funders.*

James, K. (2001) *Prescribing learning. A guide to good practice in learning and health.*

Kunsch, Jungeblut, A. Jenkins, L., (1992) *National Adult Literacy Survey in Adult Literacy*. American Department of Education, Office of Educational Research and Improvement.

Mc Dougal Jennifer (1995) *Information for Health, Access to health care information services in Ireland*, Library Association of Ireland

National Adult Literacy Agency (1998) *Access and Participation in Adult Literacy Schemes*.

National Adult Literacy Agency *Annual Referral Guide* , NALA Resource Room, Dublin 1.

National Adult Literacy Agency *Information Pack*, NALA Resource Room, Dublin 1.

National Adult Literacy Agency (1999) *Writing and Design Tips*, NALA Resource Room, Dublin 1.

Responding to the Challenge of Health Literacy The Pfizer Journal (1998, Spring, Vol 2 No.1) Salvatore J. Giorgianni, PharmD, Editor in Chief

Rollinck, S. Mason, P., Butler, (1999) Health Behaviour Change. A guide to practitioners, Churchill Livingstone.

Rudd , R., (2002) A Maturing Partnership, Focus on Basics, World Education NCSALL, Volume 5, Issue C February

Rudd, Rima and Barbara Moeykens, (1999) Adult educator's perceptions of health issues and topics in adult basic education programs. NCSALL, US Department of Education , report No.8 August

Rudd, R., Moeykens., Colton, T., (1999) 'Health and Literacy: a review of medical and public health literature' Annual Review of Adult Learning and Literacy.

The Food Safety Authority Paper (1998 October) Public Knowledge and Attitudes to Food Safety in Ireland, October.

The National Youth Health Programme – Mapping the Journey – An evaluation of the Health Promotion Youth Service Initiative 1999/2000

Towards an Equality and Rights Based Health Care System (2001) Submissions made by the Community and Voluntary Pillar following submissions and two consultation workshops

Weiss, B. Hart, G., Mc Gee D, (1992) Health Status of Illiterate Adults: relation between literacy and health status among persons with low literacy skills. Journal of the American Board of Family Practice.