

NALA Health Literacy Policy Paper

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NALA

National Adult Literacy Agency
Áisíneacht Náisiúnta Litearthachta do Aosaigh

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Introduction

Health literacy is getting attention internationally in terms of research and strategies. (See Appendix 1) NALA hopes to use this momentum to recognise health literacy an Irish health issue as currently it is a hidden one. NALA will use its experience and skills in plain English, national campaigning and integration to highlight health literacy and develop approaches and solutions.

This paper sets out NALA's focus and perspective in the area of health literacy. It outlines the work that the Agency has carried out in the area of health literacy in the past 5 years, highlights international strategies and identifies future actions by NALA that will produce change and stimulate innovative policies. It will give direction to NALA's work in the area of health literacy over the course of our strategic plan (2007-2010). Efforts to tackle health literacy will embrace a shared response: efforts will not start or end with patients.

NALA's strategic intent

NALA seeks to make the Irish health service literacy friendly where both the skills of individuals and the literacy demands of the health service are analysed. It wants to see a health service where literacy is not a barrier. It will work to influence the health service in every context: promotion, protection, prevention, access to care and maintenance.

Strategic Plan 2007-2010

The Agency's Strategic Plan has a particular emphasis on research and advocacy.¹ The Agency intends to expand the range and variety of its work in health literacy, increasing the diversity of organisations that it works with and influences. The overall policy drive is to ensure that literacy is embedded in a wide array of policy domains including health. To this end NALA will work with traditional partners such as the Health Service Executive (HSE) and other health bodies. Our work will be guided by the following objective in our Strategic Plan:

¹ NALA's Strategic Plan 2007-2010

Persuade organisations to be fully accessible to people with literacy and numeracy difficulties.

NALA's previous health literacy initiatives (2001-2006) need to be built on with a focus on research and a whole organisation approach. The Agency faces the challenge of sourcing long term health literacy funding and identifying effective initiatives for policy makers. The integration of literacy into the work of health organisations and policies will be vitally important.² Health literacy is a complex problem and needs to be addressed with a number of approaches: research, awareness and integration.

History of health literacy

NALA has engaged in health literacy initiatives since 2001, through funding from the Health Promotion Unit in the Department of Health and Children. We wanted to focus and draw attention to the difficulties that people encounter when engaging with the health service. We worked with the understanding that our work would contribute towards a health literacy policy that could be developed and implemented at national level.

HEALTH PROMOTION UNIT

In 2001 the Health Promotion Unit in the Department of Health identified literacy as a barrier to receiving and understanding health messages. The National Health Promotion Strategy 2000-2005 stated:

“poor literacy skills ...limits access to health information and health services.”

Since this time the Health Promotion Unit has supported three health literacy initiatives, all managed by NALA with a steering committee. This support has also advanced the aim of the Department's National Health Promotion Information Project which was established in 2002. One of the Health Information Project's objectives is

² Key implications for NALA's new strategy: Findings from academic/expert interviews conducted by Inez Bailey 2006.

to maximise health service providers' capacity to produce quality health information materials. This project continues to use NALA's plain English editing service and takes advantage of our literacy awareness training sessions. This project is most likely to initiate future health literacy developments.

In the past five years our work has been guided by the following objectives:

1. Increase health practitioners capacity to recognise literacy issues and design more literacy friendly material.
2. Design and produce teaching materials for literacy practitioners to integrate health into their work.

Over the last five years the Agency has:

- produced Irish health literacy research (NALA 2002) which is used as a lobbying tool;
- introduced NALA to agencies in health sphere; and
- developed expertise in developing Irish health literacy material and a family - health programme. This means that the Agency can in future advise both health and literacy practitioners in efforts to introduce health literacy.

Most of this work has involved literacy awareness training, plain English advocacy work, producing health literacy teaching materials and designing a family health model. (Appendix 2 has full details)

Health skills over health content

Up to now NALA has emphasised health literacy in the community as against clinical settings, with an emphasis on *health skills over health content*. This orientation builds on skills and initiatives located in areas such as communications and family literacy. Doctor-patient exchange is often only one part of a larger process that involves other participants such as carers, workmates and family members.

Definition of Health Literacy

The USA Institute of Medicine (IOM) and the Department of Health and Human Services emphasise a dual responsibility for health literacy and offer the most relevant definition for NALA.

“Health literacy emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing information and services.” (IOM 2004)

Researchers such as Anderson (2006) argue that it is important to examine the skills of health professionals as well as the skills of adults in our society. The responsibility for making health activities less burdensome and services more accessible should be shared. This approach and definition will guide our future health literacy work.

Role of oral skills

It should be emphasised that oral skills can be particularly important in health literacy. People are expected to be able to explain their symptoms, discuss options and interpret advice. All of these communication skills are called upon in a stressful environment. Three levels of health literacy have been identified. (See Appendix 3 for more details)

Issues to consider by NALA when developing health literacy

Funding

There has never been a fully co-ordinated effort to address health literacy in Ireland. While mentioned as a barrier to understanding in the 2000 Health Promotion Strategy, health literacy has yet to be fully recognised and researched as a health issue. As an issue it is only discussed in the realm of health promotion and needs to be tackled from a number of perspectives such as research, communications, policy, healthcare accreditation. Project-based funding can encourage over-simple outputs, which do not necessarily lead to changes.

Changes in Health Services

At present there is no national strategy driving health literacy. However the HSE is a new organisation and new funding opportunities may arise in the course of NALA's Strategic Plan 2007-2010.

Focus on Research and Awareness

In the next four years NALA will concentrate on two areas: research and awareness. Future Irish research will aid the development of health literacy initiatives. Policy makers welcome evidence-based research. NALA faces the challenge of making research relevant to practitioners and policy makers. This might mean NALA exploring funding opportunities other than the Department of Health and Children.

While the 2002 NALA Health Survey amongst adult literacy students has proved very useful in documenting people's experiences, there is no other Irish health literacy research to call on. Most health literacy statistics derive from North America. While these findings are not directly applicable outside the USA, they do indicate the range of possible impacts health literacy can have on a healthcare system. Irish research findings would allow us to develop an "evidence base" for addressing a number of key but unanswered questions. Research will generate knowledge that impels action in this area.

Ideally adult literacy needs to be included in all national surveys or it will remain a hidden problem. National lifestyle surveys like SLAN (Survey Lifestyle and Nutrition) are good opportunities to collect information and inform policy. Canadian researcher Rootman (2004) points to a number of research considerations which should be considered, such as measurement, culture, language and evaluation. (See Appendix 4)

Lack of Awareness

Lack of literacy awareness amongst medical practitioners is another barrier that needs to be addressed. NALA's 2001 research found that most medical practitioners or allied professionals were not aware of literacy being a factor in the care of patients. The next four years will see the development of a specific awareness plan directed at health practitioners in community and clinical settings.

Areas To Explore With Strategic Plan (2007-2010)

The challenge over the next three years for the Agency is to identify and carry out effective initiatives using a number of approaches. We should build on our previous work but develop other approaches. The health literacy plan will call on the expertise of various NALA staff members. Staff involved in plain English, integration, ESOL, research, awareness training and communications could be harnessed.

NALA has identified appropriate actions that can produce change. While most of these actions will be carried out with NALA as the lead organisation, other organisations will emerge as lead organisations looking for NALA's support. While the Agency does not have a specific health literacy budget it can make an intellectual investment in this issue. These actions are not definitive but will be reviewed and updated. While longterm education programmes will raise the levels of literacy skills in Ireland, we do not want to frame the issue of health literacy too narrowly. As well as health in the community, the coming years will also call for a focus on clinical healthcare settings.

The following action plan will produce four goals:

- Raise awareness of health literacy amongst the public and health practitioners.
- Stimulate funding with the HSE and other groups.
- Stimulate innovative policies which promote evaluation.
- Generate new information about health literacy in Ireland through research.

Lobbying

NALA should meet with officials in the HSE and other health bodies to bring health literacy to their attention and highlight ways in which they can address the area. These meetings will also keep NALA up to date about developments in the health sector. Some of these groups will be healthcare providers and some will work in areas where health literacy impacts on their work and are engaged in research.

Actions

- Arrange regular meetings with the Health Information and Quality Authority (HIQA). HIQA was established in May 2007 as part of the government's health reform programme. This independent authority was set up to drive improvements in Ireland's health and social care services.
- Organise annual meeting with the Irish National Health Promotion Hospital Network. Officially established in 1997 it aims to provide a structure through which all hospitals - and those working in hospitals - are assisted to undertake an active role in the promotion of health.
- Contact the National Anti Poverty Strategy (NAPS) Inter-Departmental Policy Committee which sets up interdepartmental forums with a view to exploring health literacy.
- Organise meetings with Pobal which manages programmes such as RAPID and CLAR, local area development programmes for disadvantaged areas, who engage in research.
- Meet with the relevant teaching schools in the area of nursing and medicine. This work will be very important in adding health literacy to their curriculum. This will also encourage and support teaching institutes and continuing education bodies to develop their understanding of health literacy and how it influences their work.
- Contact the Institute of Public Health to bring health literacy and NALA to their attention. The Institute of Public Health, funded by the Department of Health and Social Services and Public Safety in Northern Ireland and the Department of Health and Children in the Republic of Ireland, was established in 1999 to promote co-operation for public health on the island of Ireland.
- Contact the Irish Clearing House on Health Outcomes. It was initiated by key senior staff of health boards in December 1995. It is based at St. Camillus'

Hospital, Limerick and is part of the Population Health function within the Health Service Executive (HSE). It is a repository of projects on clinical outcomes and effectiveness studies based on practice in the health services in Ireland.

- Regularly monitor health developments in Europe by studying websites such as EuroHealthNet which is a network of health promotion and public health agencies in Europe.

Literacy Audit

Information is needed regarding the range and level of literacy skills people need when looking after their own health needs and encountering health services in Ireland. We do know that society is getting more complicated and people need more literacy skills in everyday life. We can conclude that the health sector is also demanding more literacy skills.

Actions

- Continue to explore the use of visuals in NALA's plain English work. This work will be particularly relevant to adults with poor English who might rely more on visuals.
- Analyse health actions in Ireland's National Action Plan for Social Inclusion 2007-2016.
- Design and write tools such as literacy audits that make it practical for health practitioners to make their settings literacy friendly. This will improve the understanding of what is effective communication both in written and oral form.

Communications Audit

There is an over-reliance on the written word and policymakers should take responsibility to make sure they create materials and settings that are not too complicated for the population they serve. NALA has experience in making written

and visual material more literacy friendly and therefore easier to understand for everyone.

Actions

- Seek funding to conduct an audit to ascertain the reading level of written material in a number of healthcare settings to ascertain and publicise how literacy friendly healthcare settings are. This work will involve collecting baseline data on the comprehensibility of existing forms and other materials.
- Bring this audit information to the attention of the HSE Communication Department.
- Encourage the media to increase professional and public awareness of the issues.
- Promote the use of plain English in healthcare settings.
- Research who is responsible for devising a training requirements within the healthcare system.

Awareness

Practitioners, researchers and funding agencies in the healthcare field may be unaware of the literacy problems in Ireland. Medical practitioners and administration staff in the health service need to be made aware of literacy and the link between literacy levels and health. Healthcare workers are a very diverse group and so specific promotional campaigns should be organised.

Actions

- Conduct a questionnaire amongst a selected group of health practitioners to see how aware they are of the issue.
- Design a specific literacy awareness training day for health practitioners. This day would use the findings from the above research to emphasise the role of literacy skills when dealing with the health service.

- Encourage professional organisations to make health literacy issues a priority on their policy, research and practice agendas and to develop positions and issue policy statements and papers.
- Connect health literacy issues to ongoing efforts to improve the competence and standards of healthcare settings. (healthcare accreditation systems)

Appendix 1 – International Health Literacy

Developments

USA

Much of the literature on the topic of health literacy comes from the USA and Canada. It is estimated that health literacy costs the US economy 73 billion a year. Many USA states have initiatives designed to address health literacy. The US Centre for Health Care Strategies, a non profit organisation has conducted research on the subject and Harvard School of Public Health is home to health literacy studies. Their work focuses on communication and literacy skills, exploring literacy based barriers to a variety of health services.

Research has brought greater attention to health literacy from the federal government and the medical profession. In 1998 the Clinton Administration mandated federal agencies to use plain language in their dealings with the public. In 1999 the *Journal of the American Medical Association* recognised that health literacy is critically important to health care delivery.

Findings in the 1990's from the International Adult Literacy Survey (IALS) spurred health research into links between literacy and health. Each day adults make decisions and consider issues that influence the well being of themselves and others around them. These decisions take place at work, in the home and in communities. Researchers however had not examined tasks in these settings.

Following the series of International Adult Literacy Surveys the National Assessment of Adult literacy (NAAL) in 2003 was the first large scale national assessment to include a health literacy component. The results are based on assessment tasks designed specifically to measure the health literacy of adults. Tasks used to measure health literacy were organised around three domains of health and healthcare information and services: clinical, prevention and navigation of the healthcare system. Four performance levels were devised: below basic, basic, intermediate and proficient. About 22% had basic health literacy and 14% had below basic.

Health literacy is now stated as an objective in Healthy People 2010, America's health strategy used for both state and national planning. Objective 1.2 under the area of health communication is "to improve the health literacy of persons with inadequate or marginal literacy skills." The Office of Disease Prevention and Health Promotion is the lead agency for the health communication field.

The Joint Commission on Accreditation of Health Organisations now requires that instructions be given at a level understandable to the patient. Requirements imposed by this commission and the National Committee for Quality Assurance regarding the nature and type of information used in patient education has meant greater vigilance placed on patient communication.

Canada

Canada has a national office designated to address health literacy for the nation – Canadian Public Health Association's National Literacy and Health programme promotes awareness among health professionals of the links between literacy and health. Established in 1994 the CPHA is a national independent and non profit voluntary organisation. It is composed of health professionals from over 25 health disciplines. It works with federal and provincial government departments, international agencies, non government organisations and the private sector in conducting research and health service programmes.

Having joined forces with 26 Canadian organisations interested in literacy and health, they work together to study and to hold conferences on literacy and health. They also print and make plain language health material available to health and literacy practitioners.

England

There does not appear to be much direct research into the effects of health literacy in the UK. However a strong link has been found between education and physical health. In 2003 a national research study for the Department of Education and Skills found that one in five of those surveyed had a long standing illness or disability. The study concluded that those in poor health were particularly likely to lack basic literacy skills.

In 2004 the National Consumer Council was commissioned to write a paper which summarises the main research evidence available on health literacy, information seeking and decision making behaviour in healthcare.

Some measures are in place in England to assist patients. Patient care advisers have been put in place to help with accessing services. Self management training is available to help people build their capacity for self-care as are decision support aids to assist in shared decision-making. However “their use is not widespread and further work is needed to pinpoint problems areas and ensure that the right support is available at the right times to counter inequity.” (NCC 2004)

In a collaboration between the Department of Education and Health the government launched Skills for Health to look at how health literacy could be developed amongst health care staff. A joint survey in 2004 conducted by NHSU and NIACE concluded that the “literacy and numeracy skill levels of the health and social care workforce are similar to those of the population as a whole.”

Appendix 2 - NALA's Work in this Area 2001-2006

The Health Promotion Unit of the Department of Health and Children has funded NALA's work since 2001. In that time we have:

1. produced a health strategy;
2. designed literacy friendly health materials (health pack and web-based exercises); and
3. developed and piloted a family health literacy course.



Health Strategy (2001)

In 2002 we produced a health strategy so as to document literacy learners experience of working with the health service. Whilst literacy was identified in the Health Promotion Strategy as being a barrier, research in this area had not yet been undertaken in Ireland. To ensure the strategic effectiveness of the National Health Promotion Strategy in general, and for low literacy populations in particular, policy-oriented research was required. This report documented both literacy learners and health practitioners' views on how literacy can and does influence a person's health experience.

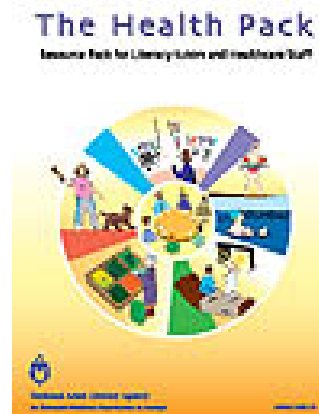
The strategy was used also to give the Agency direction and focus in terms of progressing health literacy in Ireland. It outlines and prioritises research and training areas which need to be developed by health practitioners in unison with literacy practitioners.

Health Literacy Teaching Material (2003-2006)

Health Pack (2003)

From 2003-2006 we have produced and piloted two health packs as well as a series of health exercises on our literacytools website.(www.literacytools.ie) Both resources were developed and piloted by literacy and health promotion practitioners. Tutors are expected to use both packs in the following setting

- General health
- family literacy classes
- communication classes and
- personal development courses.



Health Exercises (2006)

This pack was designed for one to one or group tuition and topics covered include: minor ailments, accident prevention and positive mental health, with exercises that then test the understanding of the information.

We piloted this pack amongst health and literacy practitioners during the 2005 summer months and made them available to practitioners in 2006 including a web version.

Health Literacy Model (2004- 2006)

NALA's Health Literacy Strategy (2002) called for more literacy friendly approaches, interventions and strategies in healthcare. NALA needed to develop practical and detailed guidelines and ideas on how to implement such initiatives. This project sought to help literacy providers incorporate health into their centre. This project sought to put theory into reality and produce a useful model for literacy and health practitioners, which we hope will be reproduced by different agencies. It is hoped this model will enhance current services and help literacy practitioners attract learners who often do not seek the literacy service.

Health promotion practitioners on the steering committee and a health promotion consultant guided literacy practitioners in developing this model with accompanying teaching materials. We produced an **evaluation** of this project. We expect it to be a very popular model which will be replicated in other literacy settings. Its approach and materials represent good practice in health promotion and literacy.

Health Literacy Handbook (2006)

Set in the context of the work of NALA and the Health Promotion Unit of the Department of Health and Children, we recommend this book to literacy, health and adult education practitioners. It has been developed from learning and experience gained during the pilot phase of the NALA Family Health Literacy Project. It provides a framework for developing programmes for different students – groups and individuals. It is aimed at people wishing to develop a Family Health Literacy stand alone programmes or courses. It can also be used to incorporate Family Health Literacy as part of other programmes. For example, it can be used within FETAC computer, childcare and communications courses.

Other initiatives have involved working with the following organisations:

- Literacy Awareness Training with hospitals and plain English editing of some health materials.
- Irish Health Services Accreditation Board
- Dental Health Foundation
- Food Safety Authority

Appendix 3- Levels of Health Literacy

Literacy is contextual meaning that different contexts will call on specific tasks. Navigation for example will call on different skills than health promotion or health protection.

Three different levels of health literacy have been distinguished (Pridmore 2001) which reflect the increasing degrees of autonomy and empowerment one can have when engaging with the health service:

- functional health literacy
- interactive health literacy and
- critical health literacy.

The term **functional health literacy** has been used to imply sufficient basic skills in reading and writing to be able to understand a simple health message.

The term **interactive health literacy** involves more advanced cognitive and literacy skills which together with social skills, can be used to manage health problems in partnership with health professionals. It involves the ability to discuss this information with health professionals, the confidence to take action and the ability to respond to changing circumstances.

The term **critical health literacy** implies more advanced cognitive skills which, together with social skills, can be applied to analyse information critically, and to use this analysis to increase awareness of one's situation and thereby exert greater control over life events. This level highlights the potential of education as a tool for social change and for political action.

Appendix 4 - Research Issues in Literacy and Health

In a world of increasing cutbacks, the gap is widening between lessons learned from research and the capacity to effectively act on recommendations.(Gillis 2004)

Canadian researcher Rootman (2004) points to a number of research considerations which should be considered, in light of up to 200,000 migrants now living in Ireland who might be experiencing difficulties using the health service. He points to issues such as definition, measurement, culture, language and evaluation raising questions which could prove useful to NALA's internal debate.

Measuring Health Literacy

The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) are the main tests of health literacy in North America. Researchers have highlighted that these tests only measure a limited range of capacities associated with health literacy. They remain little used in an international context and sparsely tested in different languages. Therefore how do we go about developing more adequate measures of literacy and health literacy ?

Culture

People from different cultural groups view both literacy and health differently. People from different groups have different life experiences which affect both their literacy and their health and are exposed to different kinds of opportunities for improving both their literacy and their health. We need to take culture into account in developing both professional practices and policies.

Language

Canadian research has indicated that “ in many cases, language rather than cultural beliefs may be the most significant barrier to initial contact with health services”(Health Canada 2001). The issue for researchers is how to disentangle the effects of language, culture and literacy on health and what are the implications for practices and policies.

Evaluation

While countries such as Canada and the USA have a strong reputation with respect to literacy and health interventions, according to Rootman “the amount of rigorous evaluation of such efforts has been minimal.” He raises the question relevant to NALA’s future work “how do we enhance the climate and infrastructure for evaluation of literacy and health efforts ?”.

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