

# Health and Social Care (Control of Data Processing) Bill

# Response from the Northern Ireland Rare Disease Partnership (NIRDP)

NIRDP is a unique partnership of those living with a rare disease; organisations representing them; health professionals; science and industry; health policy makers and academics. Our membership includes people with rare conditions ranging from the very rare, for example Trisomy 13 mosaic, to relatively well-recognised conditions such as Motor Neurone Disease, Spina Bifida, or Muscular Dystrophy. We are represented on the Northern Ireland Rare Disease Stakeholder Group, and on the UK wide Rare Diseases Advisory Group, and the UK Rare Disease Forum. We have also established strong linkages with Rare Disease UK, Genetic Alliance UK and the Rare Disease Taskforce in the Republic of Ireland.

NIRDP are dedicated to working inclusively and constructively together to find practical ways of improving the quality of life, treatment and care for those living with rare disease across Northern Ireland.

The definition of "rare disease" in Europe is one that affects less than 1 in 2000 of the population. There are between 6,000 and 8,000 rare diseases, with others being defined all the time. Over 80% are genetic in origin; many are chronic and debilitating. While each individual rare condition is rare, collectively rare diseases are not unusual. It is estimated that in the UK one in 17 people are likely to be affected by a rare disease at some point in their lives. In Northern Ireland, that means over 100,000 people: the population of Derry/Londonderry.

The scale of unmet health and social care needs in the rare disease community means that the attitude of those affected by rare disease to data sharing and secondary use is informed and progressive. We see the benefits and want to see them exploited fully; but we are also aware of the dangers and sensitivities, and want to make sure that robust and workable safeguards are in place.

It is in that context, and in recognition of the benefits this legislation can bring to the entire population, that we have compiled this response.

Yours sincerely,

Christine Collons

Christine Collins Chair Northern Ireland Rare Disease Partnership 7 August 2015



# Health and Social Care (Control of Data Processing) Bill: Why it is needed

NIRDP is pleased that support for the proposals for the Bill has led to this legislative process. We are also pleased that the Committee for Health Social Services and Public Safety has acknowledged that there is a requirement for a statutory framework to address legislative gaps and strengthen safeguards to enable the use of patient-identifiable information for medical and social care purposes, with the ultimate aim of improving health and social care which is such a vital component of each and every aspect of life.

We believe that this legislation has to be seen in the broader strategic context provided by:

- The Northern Ireland Executive's Programme for Government recognition of the inter-relationship between health, disadvantage, inequality, childhood development and education, employment, the social and physical environment, and economic growth.
- The Department of Health, Social Services and Public Safety's Report on Health Inequalities; and the resulting "Making Life Better" 10 year Public Health Strategic Framework;
- The UK Rare Disease Strategy, The Northern Ireland Statement of Intent for the UK Strategy of Rare Diseases, and The Northern Ireland Rare Diseases Implementation Plan.

We believe that reliable information shared across the "whole system", as posited in this strategic context, is an essential ingredient for the success of these policies, at a macro, regional and community level, and for the benefit of the individual. Unless reliable information, including patient/client information, is available and can be shared, then co ordinated and collaborative information based actions cannot be taken. Services will be of lower quality, have less impact and produce poorer outcomes. It is imperative that a collaborative approach is taken to the use of patient/client data throughout the health and social care system. It is clear that legislation is required for this to happen. The benefits of up to date legislation that safeguards the use of patient/client identifiable information cannot be ignored.

This legislation is URGENTLY needed to address a lacuna that has existed for far too long.

(See Annex One: The Health and Social Care (Control of Data Processing) Bill; A Significant Step Towards Better Health).



## **Definition of Health and Social Care**

We have followed the discussions in the Assembly with interest; and have spent some time analysing the provisions of the Health and Social Care (Reform) Act (Northern Ireland) 2009, and in particular the duties and definitions which apply to the Control of Data Processing Bill.

- 2(1) The Department shall promote in Northern Ireland an integrated system of
- (a) health care designed to secure improvement
- (i) in the physical and mental health of people in Northern Ireland, and
- (ii) in the prevention, diagnosis and treatment of illness; and
- (b) social care designed to secure improvement in the social well-being of people in Northern Ireland.
- 2 (5) In this Act

"health care" means any services designed to secure any of the objects of subsection (1)(a);

"health inequalities" means inequalities in respect of life expectancy or any other matter that is consequent on the state of a person's health;

"social care" means any services designed to secure any of the objects of subsection (1)(b).

So, according to the Health and Social Care (Reform) Act (Northern Ireland) 2009 "social care" means "any services designed to secure any of the objects of section 2 (1)(b)". Therefore, "social care is designed to secure improvement in the social well being of people in Northern Ireland".

This alone could be widely interpreted and leads to the possibility that the World Health Organisation's (WHO) definition of "health" might be used for the purposes of the Health and Social Care (Control of Data Processing) Bill. Whether or not the WHO definition can be used it is certainly worthy of attention in that it covers a wide range of determinants that are paramount to improving health and social care (wellbeing), and affirms the need for a comprehensive approach to data processing and therefore this Bill.

(See Annex Two: World Health Organisation definition of "health")



# The oversight Committee: controls and transparency

NIRDP also recognise the need for caution. We acknowledge that in certain circumstances there is a need for legislation that can over ride an individual's choice to opt out, even after their death. Indeed, this may be essential at a time of national crisis, for example, in the event of a pandemic. However, it is very important that the use of such information is not only "deemed" to be fair and lawful, but that the public perception of its use is that it is fair, lawful, and beneficial. We strongly believe that in the interests of good relations, of continuing improvement in health and social care through sound evidence based on reliable information, and of public confidence in the health and social care system that use of identifiable patient data is controlled in a transparent and robust manner.

The solution can only lie in ensuring stringent safeguards are in place during the application process for each usage of data through robust governance; including adherence to the Data Protection Act and the Human Rights Act. This requires the work of a strong and independent Oversight Committee working in collaboration with those who hold user identifiable information. There also needs to be openness and transparency, and clear explanation, about the controls and safeguards around the processing of information.

NIRDP have noted the concerns regarding the breadth of interpretation that potentially exists due to language used in this Bill. We agree that amendments to some of the existing language would strengthen the legislation. However we feel that it is impossible to predict every instance when user identifiable information may be needed. Flexibility is required so that this legislation can play its part in enabling the objectives of the Programme for Government, the Health Inequalities Report, and the Making Life Better Strategic Framework, especially as there is such a complex inter-relationship between "health" and economic, social and educational factors.



# Rationale for proposed amendments

# **SECTION 1: Control of information of a relevant person**

#### Section 1 (1)

1.—(1) The Department may by regulations make such provision for and in connection with requiring or regulating the processing of prescribed information of a relevant person for medical or social care purposes as it considers necessary or expedient—

- (a) in the interests of improving health and social care, or
- (b) in the public interest.

# Section 1 (1)

Concern has been raised about the "permissive" nature of this regulation making power: "The Department may by regulations.."

As these regulations will form the core of the regulatory and safeguarding regime NIRDP believe that the Department must be obliged to make the regulations; and the word "may" In the line "The Department may by regulations" should be replaced with "shall".

NIRDP is pleased to note that such regulations will be subject to affirmative resolution procedure in the Assembly, under section 4(2).

## **Section 1 (1) (a)**

The phrase in section 1 (1)(a) "In the interests of improving health and social care" could be more tightly defined, perhaps with additional wording as follows:

"in the interests of improving health and [/or] social care [in limited and controlled circumstances] as it considers necessary or expedient"

However, careful consideration would need to be given to the full implications:

- 1. Would this prevent the use of information in, for example, an exploratory analysis to identify trends or common factors?
- 2. Does the current wording ("improving health and social care) require any use of information to demonstrate <u>both</u> health and social care benefits? If so, would this be a hurdle to analyses that concentrated on either health, **or** on social care issues alone, which is undesirable?

On balance, NIRDP believe that the current wording (subject to clarification on point 2 above) should be retained.



# Section 1 (1) (b)

#### (b) in the public interest.

Concerns have continually been raised that the Bill goes beyond "the interests of health and social care" to include "in the public interest" and about the definition of "public interest" (or more accurately lack of definition). To ensure a more concrete clarification, and reduce ambiguity, the following wording:

# (b) in the public interest.

Could perhaps be amended to:

# (b) in the public interest for medical or social care purposes.

However, as pointed out in the NI Assembly debate on the Bill, 17 June 2015, defining use of identifiable information for "medical and social care purposes" alone may exclude applications made to inform education or raise awareness to protect the most vulnerable. We agree; and we believe such exclusion would contradict the holistic nature of the Programme for Government, and cut across the Committee's "Health Inequalities Report" recommendations, to place public health strategies within the context of a wider governmental strategy for the development of Northern Ireland as a region. It would exclude partnerships between health and social care and other areas of government, including departments not traditionally associated with health matters, such as the Department of Enterprise, Trade and Investment, the Department of Regional Development and the Department of Agriculture and Rural Development; reducing considerably the potential for partnerships to access Structural Funds.

Achieving the aim of rigorous and ethical regulation in an environment so dependent on a wide range of interconnected determinants as "health and social care" is very difficult.

Accordingly, we have considered an alternative approach- that is, to ask if the use of the World Health Organisation's definition of health in the Bill could obviate the need for the "in the public interest" phrase.

Under this approach the following wording in Clause 1 (1):

- (a) in the interests of improving health and social care, or
- (b) in the public interest



could be replaced with:

"in the interests of improving health"

With the definition below added to Clause 5: Interpretation

"health" means a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

(This is the Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948).

WHO's definition of "health" is inclusive of "social care" and would provide additional flexibility.

(See Annex Two: Definition of Health - World Health Organizationfor a fuller explanation).

Adherence to this definition would make it clear that the principle determinants are the well being of the individual and community and would ensure our commitment, as a constituent part of a Member State, to WHO and also to Northern Ireland's system of integrated care.

We note that the DHSSPS has examined what has been happening in other jurisdictions and the provision of 'in the public interest' has not been "invoked to any great extent" in England and Wales. It might be very helpful if DHSSPS could advise the Committee of instances when "in the public interest" has been used in other jurisdictions for research requests. For example, has this been when the information used could not change approaches to health and social care at that point in time, but could be used to inform future policies or delivery approaches? Knowing the type of applications granted "in the public interest" could provide better understanding as to whether or not the WHO definition of "health" is sufficient to cover similar requests that may be made in Northern Ireland.

#### Section 1 (3)

(3) Regulations under subsection (1) which make provision in relation to the authorisation of the processing of confidential information of a relevant person may provide that such information may only be processed if authorisation is granted by the committee established under section 2(1).

We consider it is important the Bill is clear that confidential information of a



relevant person can only be processed with the authorisation of the committee to be established under Clause 2(1).

Accordingly, we consider that this sub section should be amended to replace the words "may provide" in the phrase "confidential information of a relevant person may provide" in section 1(3) with "shall provide".

#### Section 1 (7)

(7) Regulations under subsection (1) may not make provision for requiring the processing of confidential information of a relevant person who is a recipient of services referred to in subsection (11)(a) solely or principally for the purpose of determining the care and treatment to be given to particular individuals.

## We are not sure what the purpose of this sub section is.

We have concerns that it may operate to inhibit or prevent the identification of individuals who could benefit from new treatments. In particular, individuals affected by rare diseases who may currently have very little treatment available and may need to be "tracked down" in order to enable them to benefit from scientific and other advances. For example, it has been discovered recently that some forms of ataxia are caused by gluten intolerance. Affected individuals can be identified, and the progress of the disease may be halted by a gluten free diet. In order to achieve this, it might be necessary to process information relating to **all** those currently diagnosed generally with "ataxia" or with "peripheral neuropathy" so that they can be offered diagnostic testing; and then (if appropriate) advice to follow a gluten free diet. Similar considerations could apply to processing information to identify those who had been in contact with an individual suffering from an infectious disease. It would be perverse if the legislation prohibited or inhibited in any way such processing and prevented treatment that could so fundamentally improve health and quality of life, and save costs.

#### **Section 1 (11)**

- (11)For the purposes of this Act, "a relevant person" means an individual who is a recipient of—
- (a) services designed to secure improvement—
- (i) in the physical or mental health of people in Northern Ireland, or
- (ii) in the prevention, diagnosis or treatment of illness, or
- (b) services designed to secure improvement in the social well-being of people in Northern Ireland, (including all forms of personal care and other practical assistance provided for individuals who, by reason of age,



illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances, are in need of such care or other assistance).

Concerns have been expressed about the potential breadth of this provision. We have considered this aspect carefully; and we believe it is impossible to create an exhaustive list of groups that receive services designed to secure improvement in social care as defined in the Health and Social Care (Reform) Act (Northern Ireland) 2009; or that would be comprehensive enough to comply with 'health' as defined by WHO.

To attempt to do so on the face of the Bill could (by "ruling out" under the conventions of statutory interpretation anyone not specifically included in the list) unduly restrict use of information and prevent or inhibit improvements in individual and population health. Although the examples provided in 11(b) give strong guidance to what may be viewed pertinent to consideration of "any other similar circumstances", we consider that if there is to be a list on the face of the Bill, for the avoidance of doubt carers should be included in that list. We cannot underestimate their invaluable and cost saving service, and their own needs for practical support and services.

The safeguards relating to interpretation of "or any other similar circumstances" need to be, and can only be, put into operation during the application process for data sharing, as and when each application is made and considered. Thought might be given to specifying The Code of Practice as a suitable vehicle to give further explanation and guidance.

# SECTION 2: Establishment of committee to authorise processing of confidential information

#### Section 2

- 2.—(1) For the purposes of subsection (2), the Department may by regulations establish a committee.
- (2) Where regulations under section 1 make provision by virtue of subsection(3) of that section, the committee may authorise the processing of confidential information of a relevant person in prescribed circumstances and subject to compliance with prescribed conditions (including conditions requiring prescribed undertakings to be obtained as to the processing of such information).



- (3) Regulations under subsection (1) may, in particular, make provision as to—
  - (a) the persons or bodies who are to be represented by members of the committee,
  - (b) the appointment, tenure and vacation of office of a Chair and of other members of the committee,
  - (c) the procedure of the committee,
  - (d) the payment by the Department of—
    - (i) such expenses incurred by the committee, and
    - (ii) such allowances in respect of expenses incurred by members of the committee,
    - as the Department may determine,
  - (e) the publication of any authorizations granted by the committee.

In our view, the permissive 'may' used in subsections 2(1) and 2(3), must be replaced by 'shall'.

- 2.—(1) For the purposes of subsection (2), the Department <u>may</u> by regulations establish a committee.
- (3) Regulations under subsection (1) <u>may</u>, in particular, make provision as to—

Also, we would ask the Committee to consider whether, in view of the important role this body will play in regulating the use of patient/client information, the Bill itself should provide greater clarity on its composition and powers, and its relationship with bodies with similar functions elsewhere, such as, in England, the Health Research Authority. In particular we consider that the committee should include clinicians, ethicists and patient representatives; and that this should be made clear in the Bill itself.

#### **SECTION 3: Code of Practice**

# Section 3

- 3.—(1) The Department must, as soon as reasonably practicable, prepare and publish a Code of Practice on the processing of information.
- (2) The Department must review the Code of Practice at least once in every two year period starting with the date of publication of the first Code of Practice.



- (3) The Department may revise the Code of Practice whenever it considers it appropriate to do so.
- (4) Health and social care bodies must have regard to the Code of Practice in exercising their functions in relation to the provision of health and social care.
- (5) Any other person who provides health and social care under arrangements made with a public body who exercises functions in relation to the provision of health and social care, must, in providing such care, have regard to the Code of Practice.

#### (6) In this section—

"health care" has the meaning given by section 2(5) of the Health and Social Care (Reform) Act (Northern Ireland) 2009;

"health and social care bodies" means the Department and any of the bodies established by section 1(5) of the Health and Social Care (Reform) Act(Northern Ireland) 2009;

"social care" has the meaning given by section 2(5) of the Health and Social Care (Reform) Act (Northern Ireland) 2009..

The Code of Practice on the processing of information will provide the 'backbone' for establishing robust safeguards for use of identifiable information. Given that identifiable information is only to be shared in limited and controlled circumstances, and our small population size, we feel that sharing of such information should be manageable. In order to ensure patient, carer and medical expert input into the Code of Practice, we believe the clause should be revised to read:

3(1) The Department must, as soon as reasonably practicable, and in consultation with the patients, carers and relevant experts, prepare and publish a Code of Practice on the processing of information.

It may be that the proposed Oversight Committee under Clause 2 is the most appropriate forum for this consultation, prior to a wider public consultation.

#### **SECTION 4: Regulations**

## Section 4

4.—(1) Regulations under this Act may contain incidental, supplementary, consequential, transitional, transitory or saving provision.



(2) Regulations under this Act may not be made unless a draft of the regulations has been laid before, and approved by a resolution of, the Assembly.

We are pleased that the detail around the governance arrangements will be subject to a separate consultation process that will inform the regulations. We are also pleased that the regulations will be subject to scrutiny by the Assembly.

Review by relevant bodies and the consultation process with regard the Code of Practice will be critical to achieving proper standards of care, including safeguards, in processing confidential information.

# **SECTION 5: Interpretation**

#### Section 5

5. In this Act—

"confidential information" has the meaning given by section 1(12);

"the Department" means the Department of Health, Social Services and Public Safety;

"information" has the meaning given by section 1(10);

"prescribed" means prescribed in regulations made by the Department;

"processing" has the meaning given by section 1(15);

"relevant person" has the meaning given by section 1(11).

WHO's definition of health could be included under Section 5: Interpretation i.e.

"health" means a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.



#### **Annex One**

The Health and Social Care (Control of Data Processing) Bill; A Significant step Towards Better Health.

The Health and Social Care (Control of Data Processing) Bill is essential to:

- Eliminate current uncertainty surrounding use of patient/client information other than for the direct care of the individual concerned.
- Enable organisations carrying out vital research to improve quality and equality in health and social care to do so without facing risk of legal action due to the current uncertain position on sharing patient/client identifiable information in Northern Ireland.
- Introduce safeguards and a robust framework for sharing of user identifiable information to enable better health and social care provision without mistakenly compromising patient/client confidentiality.
- Enable a collaborative approach to sharing of information, avoiding duplication and reducing cost.
- Inform assessment, diagnosis, and treatment and care of patients/clients.
- Help address the challenges the Northern Ireland community and health service face with increasingly complex health and social care needs, through enabling better understanding of comorbidities/multi morbidities/ rare disease and related specialist and palliative care needs and approaches.
- Underpin and regulate the development and use of structured registries; including development of genetic registers\*.
- Develop genuinely evidence based commissioning, service planning and service delivery in Northern Ireland- inclusive of drawing on the benefits of Northern Ireland's integrated health and social care system, strengthening the whole systems approach to care of the individual, and supporting epidemiology studies that enable continuous advancement in Northern Ireland's "Knowledge Economy", and improvement in population health strategy.
- Enable NI's participation in UK, R.o.I and international research and



development, and therefore reap the medical, social and economic benefits of Northern Ireland's unique opportunities in the field of research.

- Enable Northern Ireland to achieve international best practice standards in health and social care.
- Ultimately, reduce inequalities and provide high quality health and social care.

\*Development of genetic registers, which this legislation would help, would also facilitate increased genetic counselling for family members which impacts on long term health and reduction in morbidity and mortality, and would be supported by the Northern Ireland Regional Genetics Service (NIRGS).

#### Rare Disease and Use of Identifiable User Information

Rare diseases occur relatively frequently within the Northern Irish population, yet they are poorly understood at a population level, and the scale of their impact is not possible to assess; leading to poor planning and service provision.

Coordinated information collection on their incidence is not currently happening due to:

- The lack of legislative framework; and
- A lack of technological infrastructure to collect information on rare diseases at a sufficient granularity of detail- that of individual genetic conditions.

It is important particularly for rare diseases that information is collected at as comprehensive a rate as possible: when searching for needles in haystacks it is important to have as much of the haystack to search through as possible. This is why the non-consent model is extremely important to the rare disease community and to improving our understanding of rare diseases.

Improved information and understanding will lead to better:

- Diagnostics services.
- Opportunities to optimise potential for improved treatments and management plans.
- Population plans and allocation of services.
- Safer services for patients.



All of the above will also reduce Emergency Department and unscheduled admissions; and help achieve the vision of Transforming Your Care- the right treatment, in the right place, at the right time.

There are also broader and very significant benefits to Northern Ireland flowing from the ability to use data in improving our knowledge of rare disease.

**100K Genomes** is a UK wide project aiming to sequence 100,000 whole genomes from cancer and rare disease patients by 2017. The ambition is that the project will make the NHS the most scientifically advanced healthcare system in the world. Rare disease is now at the forefront of science and research, innovation and progress; and (once this legislation is in place) Northern Ireland is well placed to be part of this revolution in health care. Northern Ireland with its close connections and tradition of world class excellence in health issues is unique, and could play a valuable role in tackling cancers and rare diseases; so increasing understanding of all health conditions. However, there needs to be ease of access to becoming involved in UK European, and worldwide projects. This will include ensuring that funding is provided to enable individuals in Northern Ireland to have equal access to testing for genetic disorders including those offered through the UK GTN or (for very rare disorders) those offered overseas. Ideally funding could be obtained to develop high through put sequencing locally, building Northern Ireland's Knowledge Economy, improving population health, and providing high quality careers for our young people, and opportunities for our local industry.

Better understanding of rare disease is not only important to the very significant group of people in Northern Ireland living with rare conditions. It is the key to understanding more common conditions. A growing body of evidence shows that rare disease research can yield important insight into more common conditions. Rare diseases are often more extreme and have a more straightforward aetiology than their common counterparts, and therefore provide models of disease that are easier to study. Research on fundamental diseases can yield important insight into the pathogenesis of more common diseases, lead to the development of block-buster drugs, and can even explain how certain genetic mutations have become so common in today's population.

The value of truly understanding how rare diseases affect our population is tremendous. The Health and Social Care (Control of Data Processing) Bill is essential to allow data collection and analysis, and to enable that understanding to be developed.



#### **Annex Two**

# Definition of Health - World Health Organization (WHO)

The Constitution of WHO (1946) states that good health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity. Health is a resource for everyday life, not the object of living, and is a positive concept emphasizing social and personal resources as well as physical capabilities. Health is a fundamental human right, recognized in the Universal Declaration of Human Rights (1948). It is also an essential component of development, vital to a nation's economic growth and internal stability. Along with the traditional and unequivocal arguments on social justice and the importance of health, it is now accepted that better health outcomes play a crucial role in reducing poverty. There is also increased understanding of how health fits into a wider cross-sectoral, cross-border and globalized framework. Four key values guide efforts to address health issues:

- Recognition of the universal right to health
- Continued application of health ethics to policy, research and service provision
- Implementation of equity orientated policies and strategies that emphasize solidarity
- Incorporation of a gender perspective into health policies.

Health ethics involves a process of systematic and continuous reflection on the norms and values which should guide decisions about health care at the **personal**, **institutional**, **or societal level**, and by which the outcomes of such decisions may be judged.

Moral reasoning involves pursuing rules, principles, and theories. Moral rules state that actions of a certain kind ought (or ought not) to be done because they are right (or wrong). These rules are justified by basic and independent principles such as justice (fairness), respect for persons, beneficence, and parsimony (efficient use of resources). These principles reflect comprehensive ethical theories, such as utilitarianism (in which the rightness of a choice depends on whether it maximizes the good) and deontology (in which actions are judged according to their adherence to fundamental duties). Compared to medical ethics, which focuses on individuals, health ethics also encompasses the full range of health determinants and their interconnections, viewed from a societal or systems perspective.



A health determinant is a force or element that affects health, either positively or negatively. Health is determined by both intrinsic forces, such as genetics, behaviour, culture, habits and lifestyles, and extrinsic forces such as preventative, curative and promotional aspects of the health sector, as well as elements outside the health sector including:

- Economic factors, such as trade
- Social factors, such as poverty
- · Environmental factors, such as climate change
- Technological factors, such as information technology.

Global health refers to widespread health impacts that affect large numbers of people across boundaries of geography, time and culture. It includes the impacts on the global ecosystem and other health determinants, such as poverty and genetics. Global health implies a context that includes the whole world and produces its own institutional complexities.

Recently, a clear recognition has emerged that the solution to many health problems lies in addressing their root causes (health determinants), many of which are outside the direct control of the health sector. This means it is necessary to integrate effective health dimensions into other sectors such as agriculture, transport and housing, in what are called cross-sectoral policies. For example, poor housing, inadequate and unsafe water, and pollution all expose people to health risks. This requires new levels of cooperation between health and various other development sectors. However, cross-ministry and multi-donor coordination is particularly difficult in countries that are poor and when ministries lack resources to fulfil their mandate.

WHO | Health - World Health Organization www.who.int/trade/glossary/story046/en/

NIRDP believe that adherence to WHO's definition of health needs to take into consideration the social determinants of health and their significance to "improving health"- as follows:.

#### The Social Determinants of Health:

The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.



Health equity and social determinants are acknowledged as a critical component of the post-2015 sustainable development global agenda and of the push towards progressive achievement of universal health coverage (UHC). If health inequities are to be reduced, both SDH and UHC need to be addressed in an integrated and systematic manner.

Member States adopted the Rio Political Declaration at the World Conference on Social Determinants of Health in October 2011 in Rio de Janeiro, Brazil, calling upon them to act in five areas:

- Adopt improved governance for health and development
- Promote participation in policy-making and implementation
- Further reorient the health sector towards promoting health and reducing health inequities
- Strengthen global governance and collaboration
- Monitor progress and increase accountability

The Rio Political Declaration was endorsed by WHO Member States at the Sixty-fifth World Health Assembly (WHA) in Geneva, Switzerland in May 2012.

WHO | Social determinants of health - World Health Organization www.who.int/social determinants/