



INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

Glossary of acronyms and terms

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General Acronyms

AFRO	Africa region	HCP	Health care provider
AI	Average Intake	HR	Human Rights
AMRO	Americas region	NGO	Non Governmental Organisation
AR	Annual report	NTDs	Neural Tube Defects
CB	Capacity Building	ONG	Non-governmental organization
CSOs	Civil society organisations	PUSH	People United for Spina Bifida and Hydrocephalus
DPO	Disabled People's Organisation	PwD	Persons with Disabilities
EBP	Evidence-based policy	RNI	Recommended Nutrient Intake
ECEC	Early childhood education and care	SEARO	South East Asia region
ECI	Early childhood intervention	WG	Working Group
EMRO	Eastern Mediterranean region	WPRO	Western Pacific region
EURO	Europe region	WS	Workshop
FB	Facebook	YG	Youth Group
GEP	Global Experts Panel		

EU acronyms

EAA	European Accessibility Act
EC	European Commission
EDPD	European Day of Persons with Disabilities
EDS	European Disability Strategy
EESC	European Economic and Social Committee
EMPL	Employment and Social Affairs Committee of the EP
ENVI	Environment, Public Health and Food Safety Committee of the EP
EP	European Parliament
EU	European Union
EU MS	European Union Member States
MEP	Member of the European Parliament

UN acronyms

APL	WHO Priority Assistive Products List
CRC	Convention on the Rights of the Child
COSP	Conference of State Parties
CRPD	Convention on Rights of Persons with Disabilities
LoI	List of Issues
OHCHR	Office of the (United Nations) High Commissioner for Human Rights
SDGs	Sustainable Development Goals
UN	United Nations

WHD	World Health Day
WHO	World Health Organisation

ERN acronyms

BoMS	Board of Member States
CBHC	Cross Border Health Care
EPAG	European Patients Advocacy Group
ERN	European Reference Network
NCP	National Contact Point

Organisations

EASPD	European Association of Service Providers for Persons with Disabilities
ECRD	European Conference on Rare Diseases & Orphan Products
EDF	European Disability Forum
EPF	European Patients Forum
EURORDIS	Platform for Rare Diseases in Europe
EUROSTAT	Community's Statistical Office
FFI	Food Fortification Initiative
FRA	Fundamental Rights Agency (in the EU)
IDA	International Disability Alliance
IDDC	International Disability and Development Consortium
OECD	Organisation for Economic Cooperation and Development
UNICEF	United Nations Children's Fund

Glossary

Advocacy

Advocacy is a process to bring about change in the policies, laws and practise of influential individuals, groups and institutions

Average Intake

Average Intake (AI) is a recommended intake value based on observed or experimentally determined approximations or estimates of nutrient intake by a group or groups of apparently healthy people that are assumed to be adequate.

Birth defects

Birth defects, also known as congenital anomalies, congenital disorders or congenital malformations, can be defined as structural or functional defects, including metabolic disorders, which are present at the time of birth.

Campaigning

Organised actions around a specific issue and mobilising of forces by organisations and individuals seeking to bring about changes in the policy and behaviours of institutions and/or specific public groups.

CDC

The Centers for Disease Control and Prevention is one of the major operating components of the Department of Health and Human Services in the United States. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same.

Child mortality

Child mortality is defined as the death of children and infants under the age of five years old. Many of these deaths can be avoided through affordable interventions to improve maternal and child health. A child's risk of dying is highest in the neonatal period, the first 28 days of life. 6.3 million children under age five died in 2013, nearly 17 000 every day

Chronic health conditions

Chronic health conditions, also known as noncommunicable conditions, are not passed from person to person. They are of long duration and generally slow progression of symptoms or with problems of a more permanent nature. They can have a significant impact on the lives of a person and/or their family, or other carers.

Community building

National associations of SBH feel the ownership of IF and feel empowered to advocate for full respect of human rights of people with SBH, and to provide their members with high-quality support. More children and adults with SBH feel part of a global community that also includes researchers, healthcare professionals and everyone with an interest in SBH.

CRPD (also UNCRPD)

UN Convention on the Rights of Persons with Disabilities. The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. This convention is a major step toward changing the perception of disability and ensures that societies recognize that all people must be provided with the opportunities to live life to their fullest potential, whatever that may be.

Disabilities

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem.

Disabled People's Organisation (DPO)

A Disabled People's Organisation (DPO) is an organisation that is run and controlled by persons with disabilities.

Discrimination

Discrimination is the selection for unfavourable treatment of an individual or individuals on the basis of: gender, race, colour or ethnic or national origin, religion, disability, sexual orientation, social class, age (subject to the usual conventions on retirement), marital status or family responsibilities, or as a result of any conditions or requirements that do not accord with the principles of fairness and natural justice.

EDF

The European Disability Forum is an independent non-governmental organisation (NGO) that represents the interests of 80 million Europeans with disabilities. EDF was created in 1996 by its member organisations to make sure decisions concerning disabled people are taken with and by disabled people.

EPF

EPF currently has 67 members, both national coalitions of patient organisations and European disease-specific patient organisations. EPF's vision is for all patients with chronic conditions to have access to high-quality, patient-centred, equitable health and social care. Its strategic goals are health literacy, healthcare design and delivery, patient involvement and empowerment, sustainable patient organisations and non-discrimination.

EU Agency for Fundamental Rights

The European Union Agency for Fundamental Rights (FRA) is one of the EU's decentralised agencies. These agencies are set up to provide expert advice to the institutions of the EU and the Member States on a range of issues. FRA helps to ensure that the fundamental rights of people living in the EU are protected.

EURORDIS

The European Organisation for Rare Diseases EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe.

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FFI

The Food Fortification Initiative, formerly the Flour Fortification Initiative, is an international partnership working to improve health by advocating for the Flour Fortification Initiative, is an international partnership working to improve health by advocating for fortification in industrial grain mills. We specialize in wheat and maize flour and rice. The nutrients most commonly used in post-harvest grain fortification are iron and folic acid, a B vitamin.

Folic acid

Folic acid is the synthetic form of folate that can be found in supplements and added to fortified foods. Folic Acid (Vitamin B9) is a simple, inexpensive supplement which reduces the incidence of spina bifida and other neural tube defects in the foetus if taken by women of childbearing age prior to conception and for the first three months of pregnancy.

Food fortification

Fortification of a staple food with folic acid is the most efficient, cost-effective and safe way to reduce the incidence of Spina Bifida and Hydrocephalus, because it will reach women of childbearing age before they become pregnant.

Global Experts Network (GEN)

To stay informed about current developments and trends of importance in the field of Spina Bifida and Hydrocephalus, and encourage further research to improve the quality of life of persons born with these conditions and reduce the incidence of Spina Bifida and Hydrocephalus by primary prevention, IF is developing a Global Experts Network on Spina Bifida and Hydrocephalus.

Global Experts Panel (GEP)

To steer the Global Experts Network and to advise and represent IF on a broad range of matters in various areas of expertise, IF has established a Global Experts Panel. The GEP will focus on 6 domains, with regard to Quality of Life: Services and Care, Human Rights, Social Inclusion; and with regard to Prevention: Genetics, Causes and Public Health. IF President Margo Whiteford is the Chair of this Panel and facilitates the communication with the IF Board.

Health

The WHO Constitution enshrines the highest attainable standard of health as a fundamental right of every human being. The right to health includes access to timely, acceptable, and affordable healthcare of appropriate quality. Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

Health equity

Health equity refers to the absence of systematic inequalities in health. Since inequalities are so pervasive and are linked to many different factors such as biological, physical/environmental, behavioural, social, etc. The policy goal of moving towards equity in health therefore implies attempts to reduce health inequalities to a minimal level, though this minimal level may not be defined.

Health policy

Health policy refers to decisions, plans and actions that are undertaken to achieve specific healthcare goals. A health policy can define a vision for the future which in turn helps to establish targets and points of reference for the short and medium term, it can outline priorities and the expected roles of different groups, and it can build consensus and inform people.

Human rights

The Universal Declaration of Human Rights (UDHR) is a milestone document in the history of human rights. Drafted by representatives with different legal and cultural backgrounds from all regions of the world, the Declaration was proclaimed by the United Nations General Assembly in Paris on 10 December 1948 as a common standard of achievements for all peoples and all nations. It sets out, for the first time, fundamental human rights to be universally protected.

Hydrocephalus

Hydrocephalus is a condition in which the primary characteristic is excessive accumulation of fluid in the brain. Although hydrocephalus was once known as "water on the brain," the "water" is actually cerebrospinal fluid (CSF) -- a clear fluid surrounding the brain and spinal cord. The excessive accumulation of CSF results in an abnormal dilation of the spaces in the brain called ventricles. This dilation causes potentially harmful pressure on the tissues of the brain.

IDA

The International Disability Alliance (IDA) was established in 1999 as a network of global and, since 2007, regional organisations of persons with disabilities (DPOs) and their families. The aim of the Alliance is to promote the effective and full implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) worldwide, as well as compliance with the CRPD within the UN system, through the active and coordinated involvement of representative organisations of persons with disabilities at the national, regional and international levels.

IDDC

The International Disability and Development Consortium is a global consortium of 25 disability and development non-governmental organisations (NGOs), mainstream development NGOs and disabled people's organisations (DPOs) supporting disability and development work in more than 100 countries around the world. The aim of IDDC is to promote inclusive development internationally, with a special focus on promoting the full and effective enjoyment of human rights by all persons with disabilities living in economically poor communities in lower and middle-income countries.

Lobbying

Lobbying is one of the techniques and practices used as part of campaigning. Lobbying builds relationships with elected officials and tries to provide them with information, educate and persuade them to take certain courses of action when making decisions or voting on legislation.

Malnutrition

Malnutrition is a serious condition in which the body does not get the right balance of nutrients and calories needed to sustain good health and development. It arises mainly as a result of inadequate or unbalanced diets, but is also caused by poor nutrient absorption or a loss of nutrients due to illness. Malnutrition includes undernutrition and overnutrition as well as micronutrient deficiencies.

Mass fortification

Mass fortification refers to the addition of micronutrients to foods commonly consumed by the general public, such as cereals, condiments and milk.

Micronutrients

Micronutrients, namely vitamins and minerals found in natural, processed and fortified foods, are essential for normal growth and development. Micronutrients deficiencies are also referred to as “hidden hunger”. Hidden hunger can lead to mental impairment, poor health and productivity, or even death.

Millennium Development Goals

The United Nations Millennium Development Goals (MDGs) are eight goals that all 191 UN Member States have agreed to try to achieve by the year 2015. MDG 4 aims to reduce child mortality, MDG 5 to improve maternal health.

Monitoring

Monitoring refers to the continuous collection and review of information on programme implementation activities for the purposes of identifying problems and taking corrective actions so that the programme fulfils its stated objectives.

Newborn health

A newborn infant, or neonate, is a child under 28 days of age. During these first 28 days of life, the child is at highest risk of dying. It is thus crucial that appropriate feeding and care are provided during this period, both to improve the child’s chances of survival and to lay the foundations for a healthy life. Newborns with Spina bifida and Hydrocephalus are still withheld treatment in many parts of the world, owing to lack of access to quality healthcare and services.

Neural tube defect (NTD)

Neural tube defects are birth defects of the brain, spine, or spinal cord. They happen in the

first month of pregnancy, often before a woman even knows that she is pregnant. Neural tube defects affect an estimated 320,000 newborns a year worldwide. One of the most common neural tube defects is spina bifida.

OHCHR

The Office of the United Nations High Commissioner for Human Rights (OHCHR) represents the world's commitment to universal ideals of human dignity. It has a unique mandate from the international community to promote and protect all human rights. The High Commissioner for Human Rights is the principal human rights official of the United Nations.

Policy

A policy is an agreement or consensus on issues, goals and objectives which need to be addressed.

Policy maker

Policy makers are those whose professional responsibility it is to develop and organise the making of decisions in various policy making sectors. Policy makers generally refer to those employed within government (be that local, regional, national or international).

Primary prevention

Primary prevention includes any evidence-based action aimed at reducing environmental risk factors for birth defects and increasing protective environmental factors, such as national strategies to reduce the incidence of neural tube defects through food fortification with folic acid and folic acid supplementation.

PUSH Alliance

PUSH Alliance has grown out of the informal PUSH community of individuals, and now includes a wide range of global institutional stakeholders. The purpose of the Alliance is to provide a global platform for organizations committed to Spina bifida and hydrocephalus to advance prevention efforts, to improve quality of care and to eliminate disparities in access to care, through research, communication, and capacity building.

PUSH community

PUSH is the global community of People United for Spina Bifida and Hydrocephalus. The PUSH online platform is designed for its members to start campaigns, raise awareness and involve others to bring about change on issues with an impact on those living with Spina bifida and Hydrocephalus. It is a place for every individual with Spina bifida and hydrocephalus, every family, every professional fighting for better services, every individual who cares about these issues.

Recommended Nutrient Intake

Recommended Nutrient Intake is the daily intake that meets the nutrient requirements of almost all apparently healthy individuals in an age and sex-specific population group.

Social inclusion

Social Inclusion is the process of improving participation in society. Efforts are usually made to include people socially when they face situations that exclude them from society, as a result of disabilities, lack of financial means, etc.

Social media

Social media refers to online communication channels that facilitate interaction and media

distribution between people. Unlike more traditional online channels, social media allows for participation, engagement and real-time feedback on the part of supporters and constituents.

Spina bifida

Spina bifida is one of the most common types of neural tube defect (NTD) which occurs within the first four weeks of pregnancy. The spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system. Spina bifida can happen anywhere along the spine. Spina bifida might cause physical and intellectual disabilities that range from mild to severe. The severity depends on the size and location of the opening in the spine and whether part of the spinal cord and nerves are affected.

Stakeholders

Stakeholders are Individuals or groups that are affected by a decision and have an interest in its outcome.

Vitamin B12

Vitamin B12 (cobalamin) is a cofactor in the synthesis of an essential amino acid, methionine. Its metabolic role is closely linked to that of folate in that one of the vitamin B12-dependent enzymes, methionine synthase, is vital to the functioning of the methylation cycle. Deficiency of this vitamin can thus impair the utilization of folate and causes for example neurological deterioration and megaloblastic anaemia. In infants and young children it can cause severe developmental delays.

UN

The United Nations is an international

organization founded in 1945 after the Second World War by 51 countries committed to maintaining international peace and security, developing friendly relations among nations and promoting social progress, better living standards and human rights.

UNICEF

The United Nations Children's Fund, is active in more than 190 countries and territories through country programmes and National Committees. UNICEF upholds the Convention on the Rights of the Child and works to assure equality for those who are discriminated against, girls and women in particular. UNICEF works for the Millennium Development Goals and for the progress promised in the United Nations Charter, the foundational treaty of the international organisation called the United Nations.

WHO

The World Health Organization is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.