DISABILITY:
Out in the open

—

A handbook for civil society organisations seeking to promote the best interests of disabled people

Compiled by Mike Jempson

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Pam Duncan-Glancy, Eleanor Lisney,
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01

Introduction

The powerful influence of the media on our societies is well known – it shapes our views, expectations and our behaviour. The role of responsible, good quality news media is to raise awareness of important issues affecting society and defend the rights of citizens, particularly the most vulnerable and marginalized, as is the case of people with disabilities. Through their influence the media possess an enormous capacity to act as a catalyst for positive change, although many media fall short of that goal. And while civil society organisations (CSOs) share common ground with the media in addressing problems in society and defending rights, they often, like in case of FYRO Macedonia, lack the power to spread awareness. And so it is very important that CSOs learn how to harness the power of the media to campaign for their cause and change.

It is no wonder that only 17% of Macedonian citizens believe that discrimination based on disability is very common. If this data is compared with the data of, for example, education and employment of persons with disabilities, the chances of independent life, mobility and participation in policy and decision making, a huge discrepancy between perception and practice becomes very obvious. In the absence of quality reporting, the perception of people with disabilities and their needs remains dominantly subjective and susceptible to prejudice, and counterproductive. Although there are initiatives in Macedonia for encompassing the social model and the human rights approach towards disability, many of the professional and public attitudes are still reflecting the medical model, looking at persons with disabilities as objects of charity and treatment, instead of citizens with full rights, equal with others. The use of a variety and mixture of outdated terms (invalid, special needs, handicap etc) doesn't comply with the human rights based approach outlined in the UN Convention on the Rights of Persons with Disabilities and indicates the low level of public awareness.

This handbook aims at helping Macedonian CSOs that work with people with disabilities to deal with some of the challenges they face on daily basis: the absence of quality reporting on people with disabilities; the perception of people with disabilities which is often burdened with negative stereotypes and prejudice; and the lack of practical guidance on how to deal with those challenges.

The handbook is part of a 2-year programme 'Disability: a matter of perception' jointly implemented by the Media Diversity Institute (MDI), the Macedonian Institute for Media (MIM) and the National Council of People with Disabilities Organizations of Macedonia (NSIOM), and funded by the European Union.

Through this programme we want to strengthen visibility of persons with disabilities in the media thus contributing to better understanding of this particular group by the general public. But, more than anything, the aim is to send the following message: we all have endless possibilities to express ourselves and turn what others might see as 'limitations' to our advantage,

into a civil action, a good cause, an impactful piece of journalism which can change the world. Freedom to express ourselves is not only our fundamental human right which ever avenue of life we come from; it's what makes us better and richer as human beings.

The Media Diversity Institute (MDI) has been helping CSOs around the world to understand how to master techniques and approaches to attract the attention of the media, for over 20 years. This handbook is particularly focused on CSOs representing people with disabilities in Macedonia but, its content is universal and can be useful for any civil society organization operating in this field anywhere in the world.

02

Disability rights

There is a raft of international agreements which apply equally to people with disabilities as they do to other citizens:

- The Universal Declaration of Human Rights (1948)
  https://www.un.org/en/universal-declaration-human-rights/index.html
- The European Convention for the Protection of Human Rights and Fundamental Freedoms (1950)
  https://www.echr.coe.int/Pages/home.aspx?p=basictexts
- International Convention on the Elimination of All Forms of Racial Discrimination (1969)
  http://legal.un.org/avl/ha/cerd/cerd.html
  [Ratified by Republic of Macedonia in January 1994]
- Declaration on the Rights of mentally Retarded People (1975)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfMentallyRetardedPersons.aspx
- International Covenant on Civil and Political Rights (1976)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx
  [Ratified by Republic of Macedonia in January 1994]
- International Covenant on Economic, Social and Cultural Rights (1976)
  https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx
- The UN Convention on the Elimination of All Forms of Discrimination against Women (1979)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/CEDAW.aspx
  [Ratified by Republic of Macedonia in January 1994]
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1987)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx
  [Ratified by Republic of Macedonia in December 1994]
- The UN Convention on the Rights of the Child (1989)
  https://www.unicef.org/crc/
  [Ratified by Republic of Macedonia in December 1993]
- UN Principles for the protection of persons with mental illness and the improvement of mental health care (1991)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/PersonsWithMentalIllness.aspx
- International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (2003)
  https://www.ohchr.org/EN/ProfessionalInterest/Pages/CMW.aspx
- International Convention for the Protection of all Persons from Enforced Disappearance (2010)
  https://www.ohchr.org/Documents/ProfessionalInterest/disappearance-convention.pdf>

Since 2006 there has also been a UN Convention on the Rights of Persons with Disabilities (CRPD)
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

This convention was the result of over 20 years of campaigning by disability organisations. It seeks to encourage countries to introduce measures that will help people with disabilities overcome obstacles that often prevent them from being active citizens whose rights are recognised in society. This convention is about acknowledging that people with disabilities deserve respect, dignity and inclusion, which are their right as human beings.

The Republic of Macedonia signed up to CRPD in March 2007 and formally ratified it in December 2011.

Within two years of ratification, Macedonia submitted a report to the UN Committee on the Rights of Persons with Disabilities (CRPD Committee), indicating how the rights of people with disabilities are to be incorporated into legislative and social measures. The Committee responded with further questions. These were dealt with at a reviewing session in Geneva in September 2018. Civil society organisations (CSOs) had also contributed their views. As a result, the Committee issued General Observations setting out action that still needs to be taken by the Macedonian government.

Every four years Macedonia is obliged to report on progress to the UNCRPD Committee including any hindrances encountered to the full implementation of the Convention. The Committee encourages CSOs to contribute to this process. This provides an excellent opportunity to focus media attention on shortcomings in the provision of rights to people with disabilities, as well as to highlight successful progress.

CSOs are also encouraged to participate in the process of implementing these rights and ensuring that the Committee's recommendations are met.

Alongside general obligations on the state, the Convention stipulates 21 specific rights to be enjoyed by people with disabilities.

Article 5 - Equality and non-discrimination
Article 6 - Women with disabilities
Article 7 - Children with disabilities
Article 8 - Awareness-raising
Article 9 - Accessibility
Article 10 - Right to life
Article 11 - Situations of risk and humanitarian emergencies
Article 12 - Equal recognition before the law
Article 13 - Access to justice
Article 14 - Liberty and security of the person
Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 16 - Freedom from exploitation, violence and abuse
Article 17 - Protecting the integrity of the person

Article 18 - Liberty of movement and nationality
Article 19 - Living independently and being included in the community
Article 20 - Personal mobility
Article 21 - Freedom of expression and opinion, and access to information
Article 22 - Respect for privacy
Article 23 - Respect for and the family
Article 24 - Education
Article 25 - Health
Article 26 - Habilitation and rehabilitation
Article 27 - Work and employment
Article 28 - Adequate standard of living and social protection
Article 29 - Participation in political and public life
Article 30 - Participation in cultural life, recreation, leisure and sport

The purpose of the Convention is to *promote, protect and ensure* the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The Preamble of the Convention states - "Disability is an *evolving* concept, and that disability results from the *interaction* between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others." According to Article 1 of the Convention, "persons with disabilities *include* those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." There are eight guiding principles that underlie the Convention and each one of its specific articles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The articles of the Convention regulate important rights and areas. And, it is impossible to differentiate which of these rights are more important, as they are interconnected. For example, accessibility (Article 9) is a precondition for all other rights. Equal recognition before the law (Article 12) ensures meaningful implementation of the whole set of rights. Inclusive education (Article 24) is needed for obtaining suitable Work and employment (Article 27). Adequate standard of living and social protection (article 28) is needed as a basis for effective inclusion in all areas of life, while Health (Article 25) and Living independently and being included in the community (Article 19) are rights that have to be provided by the state.

Like many of the other Conventions and Declarations, CRPD has optional protocols to which countries can sign-up.

Macedonia acknowledged the Optional Protocol to the Convention on the Rights of Persons with Disabilities which allows any individual or group, who consider themselves to have been adversely affected by the state's non-compliance with the Convention, to seek redress via the CRPD Committee.

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) adopted by the UN in 1979 intersects and is closely associated with CRPD. CEDAW provides the basis for realising equality between women and men by ensuring women's equal access to and equal opportunities in political and public life, education, health and employment, and women's rights to acquire, change or retain their nationality and the nationality of their children.

States party to CEDAW agree to take appropriate measures, including legislation, so that women can enjoy their human rights and fundamental freedoms, and to act against all forms of trafficking and exploitation of women. CEDAW also affirms the reproductive rights of women and targets culture and tradition as influential forces shaping gender roles and family relations; this is especially important when taken in conjunction with CRPD's Article 6 that recognises intersectional discrimination faced by women with disabilities.

As the UN has pointed out in the past, "ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development."

The concepts of 'handicap' and 'disability' themselves reflect limitations arising from discriminatory attitudes within the general population, and the design and structure of the physical environment that, in effect, 'disable' certain individual citizens. With the help of the 'social model' of disability, we understand this better now.

Article 9 of the Macedonian Constitution asserts the equality of all citizens, and Paragraph 3 of Article 35 obliges the State's to create inclusive conditions in society for people with disabilities. That includes appropriate arrangements for children with disabilities to enjoy the same educational

facilities and opportunities as other children. Inevitably that must also involve improving awareness within society of the needs and rights of all citizens with disabilities of whatever kind.

Macedonia appears to comply with the requirements of the EU Framework that promotes and monitors the implementation of CRPD among member states. The state acknowledges the importance of the family unit, and the need for both counselling and other forms of support for family members as well as for those with sensory or intellectual disabilities, and the need to facilitate the engagement of people with disabilities in cultural, leisure and recreational activities.

It also notes the importance of preventative measures to reduce the extent or likelihood of disabilities through primary health care, immunisation, and health and safety measures to combat injuries at work and environmental pollution, as well as the provision of appropriate health care for those with disabilities, and rehabilitation facilities for those seeking to regain mobility, for example, in order to live more independent lives. This includes creating favourable conditions in public sector workplaces and encouraging the private sector to do the same.

The 2015 European Accessibility Act should have made it easier for people with disabilities to obtain equipment designed to enhance their ability to be fully functioning citizens by removing barriers that could hinder companies from producing and distributing accessible products and services. Nor should people with disabilities be put at a disadvantage in the provision of social insurance, social assistance and social protection.

The act also obliged the State to ensure that people with disabilities and their families are made aware of their rights and expectations. State and private institutions need to be fully informed about the rights and appropriate provisions for people with disabilities. Professionals dealing with them, including employers, need to keep abreast of developments in the field of social and health care, scientific research, equipment and the law as they relate to the needs of people with disabilities.

The media have a significant role to play in this process. It is important that both the State and CSOs engage with the print, broadcast and online media to disseminate relevant information. This should include making appropriate arrangements to communicate with individuals with sight or hearing impairments, as well as easy-to-understand formats for those with intellectual disabilities. In particular, this responsibility applies to mainstream media and the cultural industries, including museums, art galleries, theatres and cinemas, as well as sports venues and other facilities where physical access may be required.

Macedonia is now committed to ensuring that individuals with severe intellectual disabilities or multiple disabilities, should be accommodated close to family homes, in order to limit the anonymity and neglect associated with larger centralised institutions. Similarly, it seeks to make more appropriate provision to support individuals with autism and cerebral palsy.

The State is also expected to take into account the needs and difficulties faced by people with disabilities in its collection, storage and protection of demographic data, especially in relation to the development of policies and law, in order to identify and take measures to eliminate discrimination against people with disabilities and to meet their needs.

This includes ensuring that people with disabilities are able to form their own organisations, which should be consulted by the authorities especially in relation to their specific needs, and to ensure that they have equal representation on relevant state bodies, more generally.

On the national level, the 2010 Anti-discrimination Law enshrined the rights of people with disabilities in Macedonia, and made the Commission for Protection against Discrimination (CPAD) responsible for protecting these rights. Although there is no charge for taking cases to the CPAD for adjudication and recommendations for action, there has been a decline in its use in recent years despite reforms to its procedures.

Cases can be brought directly or subsequently through the courts, but even if there is a finding of discrimination it can only result in a fine rather than rectification of any processes that have caused the discrimination in the first place. Between 2011 and 2016, the Commission received 44 complaints about disability issues and acknowledged discrimination in only 3 cases. In the same period only one case was taken to court, where it was ruled that discrimination on the grounds of disability had taken place.

Another alternative is to seek a ruling from the Ombudsperson. However, relatively-few cases about discrimination on the grounds of disability have taken this route.

Autism

The party: a virtual experience of autism
https://www.youtube.com/watch?time_continue=90&v=OtwOz1GVkDg

The Chameleon: Women with Autism
https://www.youtube.com/watch?v=VJHa9xk16Hw

Launch video
https://www.youtube.com/watch?v=mLOwy9mm-c0&frags=pl%2Cwn

Eleanor Lisney
Freelance Journalist

„No rights have ever been granted by waiting patiently for attitudes to change."

Demanding our rights

'Society' defines disability by failing to organise itself so that no-one is disadvantaged. In the UK under the 2010 Equality Act, you are defined disabled if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

As a result of the polio epidemic that happened when I was a child, I have a mobility impairment and use a power wheelchair. I've had mobility issues since I was 3. As I grow older I have to get used to more impairments because of age, wear and tear to the body. But the experience of living with disability does not change because, using 'the social model', it is not dependent on my particular impairment. It is dependent on barriers caused by my environment and by society's perceptions of what I can or cannot do as a disabled woman, and whether I am given reasonable adjustments in the way I live my life.

For example I have post-polio syndrome. This gives me chronic fatigue. So, sometimes, I can't perform to my optimum capacity and it is annoying to have to tell people and equally annoying because you can't live up to your own expectations.

People do not always understand that much of your income has to be spent on expensive equipment, and time and energy on maintaining physical and mental health, not to mention the extra organisation you need to balance everything.

The most annoying thing about it is not having the right type of support, as well as government cutbacks and

people's attitudes. The right sort of support would be having the financial ability to purchase the equipment I need, and paying for the support that is required to help me work and live independently.

The media have an important role to play in making life more equitable for people with learning difficulties, physical or sensory impairments. They should use appropriate language for a start, and avoid the language of pity and 'inspiration porn'. Very often journalists just take quotes from social media instead of interviewing disabled people themselves. In addition, people with mobility issues are not always the best people to interview about the barriers that people with mental health issues face, and vice versa.

Media professionals should do proper research when covering disability issues, and ask disabled people for their views and for the correct terminology. Their lived experience should direct media narratives. For example, disabled women face the same patriarchal society as other women with the added barriers that disability brings.

According to research by the campaign group Sisters of Frida in the UK:

- *35% of disabled women (and 30% of disabled men) are paid below the National Living Wage in the UK.*
- *Disabled men face a pay gap of 11%, while disabled women faced a gap twice as large at 22%.*
- *Despite having the right qualifications, disabled women have lower participation rates in higher skilled jobs and work fewer hours than both non-disabled women and disabled men.*
- *27% of disabled women are economically inactive compared with 16% disabled men.*

I work as a writer and, mostly, in new media. I belong to the National Union of Journalists, and my branch (London Independent Broadcasting New Media) is very supportive of me both as a disabled and as a woman journalist.

I am a campaigner first and foremost. No rights have ever been granted by waiting patiently for attitudes to change. We need to use existing legislation to demand our rights under domestic law and international conventions.

Francesca Martinez

Comedian and campaigner

Franesca has had sell-out shows in America, Australia, Canada, Ireland, Malaysia, Singapore and South Africa, as well as her native United Kingdom.

Diagnosed with athetoid cerebral palsy at the age of two, she explains to audiences that she is a 'wobbly'.

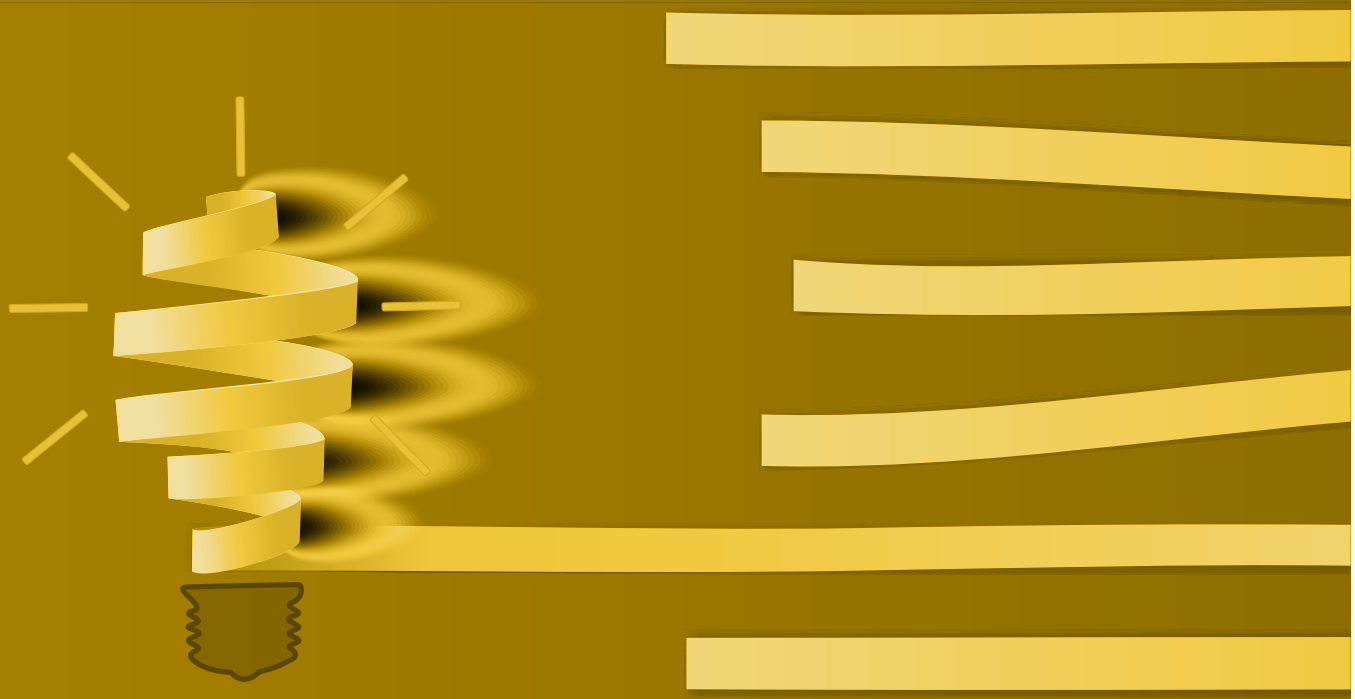
An outspoken campaigner for welfare rights she says "As a disabled person in the media, I want to help give this issue a voice. It's morally wrong for the government to target those in need instead of saving money by targeting the real causes of this crisis – and close tax loopholes and regulate the financial sector. To me, it's a human rights issue."

Regarded as 'abnormal' at school, even a part in a popular TV soap opera did not mend her self esteem. But stand-up comedy did.

She says: "It became clear why this mass worship of conformity dominates our culture… it's because our society is built on consumption. And consumerism will only thrive if you can convince enough people that they're lacking in some way, and that what they really need is the latest product/outfit/look to be 'normal'. That's it. We're sold this lie so that we'll keep buying crap that we don't need. So that we'll continue to attempt to attain "normality" through purchases and surgeries and upgrades and iShit. Incessant advertising gnaws away at our self-worth and then generously steps in to fill the gap. Again and again. But this empty cycle of acquisition and obsessing about trivialities just leads to debt, unhappiness, and a deep dissatisfaction with our lives and bodies. It is a culture that is fundamentally at odds with the fact that difference and disability are a natural, normal part of life."

03

Media strategy and media policies



Every civil society organisation wishing to effect social change needs to know how to deal with the media. These needs will differ from time to time, but it is best not to wait for a crisis before deciding on strategic objectives and day-to-day procedures for handling media relations. Below is a framework for dealing with these needs.

Media strategy - How, when and why are we going to seek publicity and make use of social media?

Media policies - Clear internal procedures about who handles the media, and how.

Dealing with the media requires skill, tact and knowledge of the media as well as the organisation's aims, messages and specialisms. All managers, staff, volunteers, or members need to know about the organisation's approach to media relations, and who is authorised to talk to journalists.

Spokespeople are the human face of the organisation. Ideally a spokesperson should be clear, credible and interesting. They should remember that tone of voice and body language can be more important than actual content - a pleasant personality can be the most effective advocate. Different media situations also call for different types of 'front' people. Sometimes, the most senior person may not be the most appropriate: someone who is skilful at chairing meetings may not be very telegenic. Such complications need to be considered and resolved as a matter of course, so there are no problems when the situation arises.

First of all, the organisation needs to be clear about what sort of publicity it wants, and why. Then it must work out how it is going to get it, and how it will make best use of the publicity for both its campaigns and its own public relations.

To devise a thorough media strategy and policy, organisations should answer the following questions:

1. Why do we need publicity? (Is it, for example, to educate the public? Influence policy? Help with fundraising? Satisfy sponsors? Or, something else?)
2. How often do we seek publicity, and for what purpose?
3. How often are we approached by journalists? And, what do they want to know?
4. Do we have the (human and financial/budget) resources to achieve our strategic media aims and media objectives?
5. Do we have an up-to-date database of contacts in all the relevant media outlets - newspapers, magazines, trade journals, websites, radio, television, social media?

6 Have we devised (and written down) basic procedures for how to deal with media enquiries? Who is best suited to represent the organisation, especially in times of crisis?

7 Does our appointed Press/Public Relations Officer have appropriate training, and easy access to everyone within the command structure of the organisation?

8 Do all public statements on behalf of the organisation have to be cleared by the Chairperson/ Chief Executive, and issued in their name/s?

9 Do all documents issued by the organisation clearly state the objectives of the organisation? Do they supply valid sources to back-up the claims made in the document?

10 Are there clear guidelines to ensure that the personal details of our clientele are not divulged to the media, unless they have given their express consent that their story can be used, and have been properly prepared to deal with subsequent media enquiries?

11 Do our publicity events reflect the core values of the organisation (for instance, if we are seeking sponsorship, are there guidelines to ensure that our objectives cannot be compromised by the activities of potential sponsors?).

12 Do we have an effective system of monitoring our media relations - keeping a record of media coverage, and responses to it (requests for information, donations, criticism, further media enquiries) and reviewing it annually?

Draft Media Strategy & Policy for a civil society organisation dealing with disability

Our aim is to improve public understanding and to increase public awareness of the social conditions that prevent people with disabilities from fully engaging as citizens.

To achieve this objective, we need to build a positive public profile both to promote our message and to attract funding.

We shall seek publicity for all aspects of our work by
- *issuing regular news releases and authoritative background briefings;*
- *producing accessible summaries of our research findings;*
- *responding promptly and professionally to all media enquiries;*
- *supplying evidence in the form of personal appearances by our clients.*

An appropriate part of the budget shall be set aside each year to ensure the implementation of this strategy.

Responsibility for devising and issuing press releases, organising public events and publicity campaigns, and handling media enquiries will rest with the Press and Publicity Director (and staff) in consultation with the Chief Executive.

Whenever possible, publicity should focus on the agreed priorities of the organisation at that specific time.

In the first instance, all media enquiries must be directed to the Press and Publicity Officer.

The private numbers of clients or committee members must not be issued to journalists.

No member of our clientele, staff or management shall be expected to engage with media professionals without advance warning, preparation and training, as appropriate.'

Anita Bennett
Campaigning journalist

"The families of those with learning disabilities are crucial. Their predicament and their views need to be heard."

Don't forget the carers

*My daughter Isabel has Down syndrome. Aged 31, she looked at the disability logo commonly found in all public places and protested, "But I'm not in a wheelchair, am I? I have a **learning** disability."*

The 'social model' of disability now dominates official thinking and policy in the UK. As a result, the concerns, practical experience and personal dilemmas of the carers are often ignored. Many of us believe that the interests of those with learning disability are best represented by their immediate families.

Indeed, the majority of carers are single mothers, since relationships rarely take the strain involved, nor the poverty and ill-health associated with looking after those less-able to fend for themselves. This makes it a profoundly feminist issue.

Ignoring family advocacy, and neglecting to advocate for carers, could have negative consequences for those they care for. While closing badly run and poorly-funded institutions may be important, doing away with them entirely may have not be the best way to promote the best interests of people with learning disabilities.

Some cannot cope in mainstream schools, and specialist schools with small classrooms have helped many to reach their potential and maintain friendships with peers.

*The voices of families like those I represent in Rescare, the UK Society for Learning Disabled Adults and Children and their Families, have been drowned out by those who insist that the 'social model' - mainstreaming and small houses - is the **only** way to regard and provide for all people with disabilities.*

In addition, the views of doctors – accused of promoting a 'medical model' – have been supplanted by those of Social Services who have virtually replaced the National Health Service in the UK as a provider of what was lifelong care. As a result, women now do all the caring alone.

It was clear to me that, as a child, Isabel needed a residential special school. The local primary school was not for her after she was seven, and I was trying to support three children on my own. When I tried to advocate for my daughter I was met by the 'inclusion-at-any-cost' philosophy: "Mainstreaming for all is our policy, not a special school for Isabel. We believe in the family as the only right model of care, not any big institution. So, we will put her in foster care."

When it was discovered that she was being sexually abused in the municipal weekend respite care scheme, their argument collapsed. She was made a Looked-After Child (fostered), and then given a place in the wonderful Steiner Camphill Sheiling School. This enabled me to go back to work in journalism, and to train as a teacher of the Alexander Technique.

There are Camphill Communities across Europe and Russia which are worth studying as a more holistic and inspiring model of live-in care. The historic idea of society taking some collective responsibility for our special citizens is better understood there, than it is in individualistic, materialistic capitalist societies, where the nuclear family is expected to bear the brunt of caring, and risks collapsing under the weight.

At another stage in Isabel's development I could not afford the huge cost of applying to become her Welfare Deputy (a court appointed advocate). Without consulting me, the local municipality appointed their own advocate to represent Isabel's interests. The assumption was that her mother was incapable of being entrusted with a responsibility she has carried for 30 years. I was faced with a total stranger apparently manipulating a vulnerable young woman's future. Since residential care is increasingly in the hands of private providers, it was hard not to imagine that decisions were being taken to benefit the provider rather than my daughter.

In the private institution she was allocated by the court, my daughter had put on more than 16 kilos in only 6 months, and was being allowed to oversleep the mornings which meant she was missing Spanish and literacy courses it had taken years to organise. While someone with full mental faculties, for example a person with cerebral palsy, can be expected to make a capacitated decision about missing an activity or moving home, a woman with Downs will often say what she thinks people want to hear.

The attitude of the home, where the main extra-curricular activity was a trip to the super-market, was that Isabel was choosing to stay in bed. In the Camphill Community to which I had hoped she would return, there was meaningful work and genuine friends, rather than staff paid to befriend her. There Isabel had always been keen to get up and join in.

For three years I worked in 30 homes run by charities for those who had been forced out of the eight mental handicap hospitals, often against their families' wishes, and into much

smaller places. That is where Rescare began, lobbying for families to be consulted. Many of the staff I worked with had been trained in the hospitals; all of them agreed that life in the hospitals had been far better for people with learning disabilities than their current circumstances.

At the hospitals, they had enjoyed a wide circle of friends. They had responsibilities, were not called 'clients', as they are today. They had jobs, gardening, cooking, laundry, etc. They performed in drama theatres, and had prescribed occupational therapy, much as GPs are recommending today. NHS staff had career prospects then. Today, low-paid support workers are stuck in often lonely jobs leading nowhere, except possibly into managerialism. This has been a significant factor in recent human rights scandals in care homes across the country.

In the days of the NHS hospital provision only about 10% of people with learning disabilities were catered for. Most stayed at home with ageing parents who worried about what would happen to their child when they died. The authorities did not have to worry about the needs of the carers or their children until the inevitable happened. Research indicates that siblings suffer more guilt, depression, marital breakup, etc., because of everyone's assumptions they can and will take over.

People with learning disabilities don't need a lot of meaningless choices, about watching television, for example. They need a lot of push, and group drive, peer pressure, if they are not to deteriorate into obesity. This best antidote Isabel and I have experienced was in a Camphill Steiner community setting. It was her residential special school for over ten happy years. It was a long way from contemporary received wisdom that people with disabilities should live in their own homes with professional carers coming in. Applying this ideology to people with severe learning disabilities may be far from a satisfactory approach.

Social attitudes and barriers may further stigmatise people with disabled children, but why does every pregnant woman have a test for Downs if it is not a medical condition? Is a speech defect really the fault of 'society not accepting the disability'? Or might there be a valid medical need for intervention?

Nowadays, families struggle to get a speech therapist at mainstream schools. The more holistic model of disability at Camphill worked so well for Isabel, because speech therapy was part of her school day memorising poetry and verses.

My point is simple, the families of those with learning disabilities are a crucial part of those lives. Their predicament and their views need to be heard officially, alongside the voices of those with physical and learning disabilities themselves.

04

Dealing with the media

Most people feel awkward when dealing with the media. To non-journalists, media professionals often seem like distant beings invested with special powers. While it is true that some have over-inflated egos, the vast majority are in fact ordinary working people who happen to have particularly good communication skills. They are in the business of story-telling, so they need you as much as you may sometimes need them.

Don't be afraid to make contact, especially when you see material that impresses you. Few people ever thank journalists for their work. If you let them know by phone or email that you liked an article or programme, they will be flattered. If you explain your particular interests and that you might have stories for them - you and they have made a valuable connection. Make sure you give them your contacts details.

It is more likely that you will be seeking publicity. You should prepare a Press Release when you have something new to tell the public. In writing it, you should remember that the journalists you send it to are your primary audience. It needs to be written to excite their interest, and persuade them to take-up the story. Today, press releases are more likely to take the form of emails, either as straight messages or as attachments. Given that journalists receive a barrage of emails everyday, you should ensure your press release is brief and excites their interest in some way.

A. Different types of Press Release

The Advisory or Calling Notice gives advance warning to the media that something will be happening soon — so they can make a note to cover it in their diary. It must be followed up with a more detailed News Release.

The News Release provides the basic information needed for journalists to understand what is about to happen – the launch of a new campaign, the results of a study, or a publicity event.

The photo-call announces that something visual or someone photogenic is available at a certain time and place, **so** the film crew or photographer can come and get good pictures. This information can be incorporated in a Calling Notice or a News Release.

The Press Statement offers your instant response to a recent news event or an announcement that, for instance, a politician or celebrity have made. It is your contribution to the debate. It would normally offer either an endorsement or critique of what has been said, and provide evidence to support your point of view.

The Press Briefing is a more substantial (but not complex) document providing background to an issue or an event. It is designed to help the journalist understand and explain the significance of an issue or an event to members of the public. Journalists who are interested but not expert in your field will find these very helpful. Sending a press briefing can increase your credibility as a 'source' or contact for them. It is especially useful for explaining why a particular piece of legislation is important or problematic.

Never take it for granted that your press release has been received or read. Always follow it up with phone calls to the appropriate person on the programme or publication you are targeting. Ask if they have seen it, and try to get them interested – be ready to send another copy if you get them hooked.

Information is different to **news.** However accurate your facts and figures, to a journalist they are simply data. What journalists need is 'context' and preferably access to someone who can tell a story, which will illustrate the issue or information you want to publicise.

Serious journalists will not act as publicity agents. But if you have a good story to tell, they will be interested in passing it on to the public.

B. Writing a News Release

It may make senses to send information as an attachment to an email, rather than put it in the body of the email directly, because a well-organised document with your company's logo and contact information establishes a 'brand image' that is immediately recognisable and is easier to read. However, you will need to alert the recipient why opening the attachments will be advantageous. Opening an attachment is an extra task, and it has to be worth-while.

Design your releases so that they can be distributed in hard copy or by email. And make sure they contain your distinctive logo and/or campaign slogan.

Ten top tips for Press Releases

1. Use an official document template with letter head, to give authority to your message, and make sure it includes all your address, telephone, email and website details.
2. Include the date of issue, a reference number (so you can refer to it later), and where possible indicate who it is intended for – by name or title, eg Social Affairs Editor.
3. Give it a short, simple headline that 'tells the story' – and try to tell that story on a single page.
4. Start with the basic essentials, making sure to answer the essential journalistic questions – Who? What? When? Where? How? Why?

5. Include a ‘quotable quote’ that contains your key message, with the name and status of the speaker.

6. In the rest of the release provide more detailed information which helps to explain the significance of the subject matter.

7. Always give a contact name and telephone number (24 hours)

8. If you think you can provide journalists with images that illustrate the message of the story include a short note, and suggest a time and place for a ‘photo-opportunity’.

9. If you want to communicate with a specialist/local audience, use the appropriate media. A good journalist will recognise a story that might also be told or sold to a wider (regional/national) wider audience.

10. Always think about who your target audience is – and try to write your release so that they will understand it. Highly-technical material should only be sent to a specialist publication.

Do

- Check deadlines in advance — allow journalists time to make their own enquiries;
- Use headed note-paper, include the date and a punchy headline;
- Try and keep it to a single sheet;
- Number the pages; indicate at the end of each page if another follows; start each page with a new paragraph, and on the final page finish off with ‘ends’;
- Get all the crucial information in the opening paragraph/s — who, what, when, where, why, how;
- Include a succinct ‘quote’ from an identified spokesperson;
- Provide a contact name and a (24 hour) phone number — make sure your spokes person has a copy of the press release, and can be reached outside office hours;
- If your story has a strong visual element, say when, where and what type of photos can be taken;
- Indicate where additional background material might be found;
- Follow it up with a phone call — if it hasn’t been received/read deliver a copy at once.

Do not

- Send anything out before a colleague has checked for sense, accuracy, and spelling - mistakes damage your credibility;
- Assume the reader will know all about your concerns;
- Obscure your message by including complex or figurative prose or irrelevant details;
- Use repetition, clichés, jargon, and abbreviations;
- Exaggerate, or make claims you cannot prove - overstating your case is more likely to weaken than strengthen your position;
- Include defamatory statements — you are liable for the libel;
- Ignore media interest generated by your press release — you have sought their attention, so return their calls;
- Use irony — it seldom works with strangers, and wit is more effective;
- Assume your release has been received until you have spoken to a journalist who has read it.

Bad example

For attention of the Editor **Bledski Dogovar, Skopje**

Monday 1/12/18

The Skopje Branch of DRIM has been holding a series of very well attended and successful meetings in recent months to discuss its forthcoming plans. Members came up with plenty of different initiatives, and after a lot of discussion we agreed a plan of action for the rest of this year.

On Human Rights Day we shall be gathering in Mother Teresa Park for a demonstration and march to the Parliament Building which we shall encircle with joined hands for a symbolic sitdown protest against government policy.

We are calling on all concerned citizens to join us and make a day out for all the family of this unique event which we believe will provide an opportunity for ordinary people to vent their anger about the heartless attitude of many politicians to the plight of disable people everywhere in our country.

We sincerely hope that your newspaper will help publicise this important event, and report fairly on public outrage about the issues.

In solidarity with the disabled.
K. Nedelkovski, for DRIM

Commentary

Earnest, rambling, verbose — and unclear. No quotable quotes, but its message is certain to make the authorities view the event with suspicion.

The tone suggests violence and the first call the press are likely to make will be to the police to see what they know about it.

And anyway, what is DRIM? When was this written? When is Human Rights Day? At what time will the event start? Who is K. Nedelkovski? Where is the contact number, so journalists can find out more?

A Press Release that raises more questions than it answers is not 'fit for purpose'. To be effective a Press Release should have the reader saying, "Tell me more!" not asking "What's this about?"

Better version

Disability Rights in Macedonia (DRIM)
Bledski Dogovar 14, Karposh 3, Skopje

Press Release: 004
1 December 2018

DRIM campaign to celebrate Human Rights Day

Supporters of Disability Rights in Macedonia (DRIM) will join hands around the Parliament Building on Human Rights Day, Monday 10 December. This symbolic gesture of solidarity will launch a new campaign to encourage Macedonians to help end discrimination against disabled people.

Local community groups have been invited to join DRIM members at midday in the Park of the Woman Warrior, for a festival of folk songs before processing to the Parliament building.

"It will be a celebration of the global community of disability activists with music as our international language," says DRIM Secretary Maja Jordanova. "Children are especially welcome."

DRIM chair Kosta Nedelkovski told a packed meeting at the weekend: “Ignorance, fear and prejudice have made life difficult for disabled people for too long. We want the people in Skopje to show they care by bringing their children and wearing colourful clothes to share the day with our disabled members and show our politicians that the time for talking is over. We want concrete evidence that things are changing for Macedonian citizens, whatever their abilities or impairments.”

Other events on the day include a minimarathon along the banks of the Vardar, a children’s conference at the Mother Teresa Memorial House, and the making of a massive community quilt which will be assembled in the Sacred Heart Cathedral during the day.

For more details contact Kosta Nedelkovski on +389 2 1234 567
or Kosta Nedelkovski on +389 2 9876 543

Note to Editors

DRIM is a non-existent independent network set up solely for the purpose of this press release.

Commentary

Succinct, clear, non-threatening, and eminently quotable.

This release is designed to get POSITIVE coverage, and provides all the necessary information — details of essentially visual events, with names, dates, contact numbers and good quotes.

C. Press Conferences

A **Press Conference** is a gathering called with the specific intention of providing the media with opportunities to display important, new information or to question key figures about an issue. If it is run well, you gain publicity and both journalists and the public learn something new.

To be effective a Press Conference needs to be planned carefully and run efficiently. It is a waste of everyone's time if the information could be supplied to journalists in a simpler way – for instance with a press release or a phone call. It should always be visually compelling, to make the attendance of photographers and TV crews worthwhile.

Make sure that there is up-to-date information about the time and place of your event/press conference on your social media platforms (Facebook page, Twitter and Instagram). If you have an appropriate hashtag for the event/campaign/action, make sure you use it and ask journalists to use it.

i. Planning

Before you start, answer the following questions:

- Why are we calling a Press Conference?
- Is there an easier, and cheaper way, of informing journalists? Press releases? Phone calls?
- Do we have the resources to make it an impressive event?
- Have we got something new to present? For example, a research report or some new evidence about an important issue.
- Is it visual enough to attract cameras? Will public figures or interesting personalities attend the event? Do you have attractive visual material? People? Posters? Videos? Charts?

If you decide to go ahead think carefully about:

- **Timing**

  - Make sure you organise the event to fit in with any follow-up plans you have. For example, it is no good to announce a campaign if the campaign literature is not ready to go out
  - Make sure your set it on a day that fits in best with the deadlines of the publications and programmes you want to attract;
  - Hold the event at a time that will allow journalists to get information back to newsrooms ahead of deadlines. It is a good idea to try to get on the lunchtime radio/TV news – items reported then are more likely to appear on the news later on the same day.
  - Make sure your keys speakers will be available to do interviews later on the same day. Journalists won't be happy to find that potential interviewees rush away as soon as their presentation is over.

- Plan for the formal presentation AND questions to last no more than an hour; if you have a panel of speakers each person should not speak for more than five minutes.
- If you are using key speakers, supply journalists with copies of their intended speech (to be 'checked against delivery') and brief biographical details.
- Make sure there is plenty of time for journalists to ask questions. Their stories will often be based around the answers they get.
- Don't be surprised if journalists try to change the subject. It is their job to find an angle, so speakers should be prepared for that eventuality.

• Venue

- Make sure the location of the press conference is accessible, easy-to-find and well-marked. Send journalists a map if necessary, and indicate whether it is wheelchair accessible.
- Try to have a reception area outside the conference room, for registration, serving refreshments and greeting latecomers without disturbing the main event.
- Make sure it is big enough for your purposes. There needs to be room for TV cameras to set up and photographers to move around.
- If possible, ensure there are quiet places where one-to-one interviews can take place if required.

• Resources

- Make sure your materials (reports, leaflets, stickers etc) are ready and available on the day.
- Make sure your equipment (microphones, computers, projectors, videos, lights etc) is tested and working before the event starts. Also, make sure there are power sources available for media technicians.
- Make sure you have enough people to greet and accommodate the needs of your speakers and journalists, some will want to book interviews, etc.
- If possible, arrange name badges in large font so that everyone knows who is who.
- If you are serving refreshments make sure they are ready to be served as soon as people arrive. A convivial atmosphere allows people to talk and network – one of the most important aspects of the event.

• Speakers

- Choose someone to chair the event who is a confident public speaker, and knows enough about the topic and the other speakers.

- Make sure your speakers are properly briefed – ahead of the day and again on the day itself. They need to know the purpose of the event. What points they need to emphasise (and possibly what NOT to say!), and whether they might be expected to do interviews after the event.
- Ask speakers to prepare a written version of what they are going to say - a brief document can be distributed to journalists on the day and which journalists can quote and 'check against delivery'.
- Journalists do not want to hear long speeches, they want to be able to ask questions. Your speakers could refer to the printed version and just focus on a couple of important points during delivery.
- Make sure speakers are prepared to answer questions about everything that is in their printed speech, AND any related topical issues that are current.
- In preparing for the event think about what OTHER issues might be raised by journalists. What related stories are happening at the time? Prepare speakers to deal with them or even to politely refuse to discuss other issues.

Picture Credits: Ray Burmiston

"I don't mind talking about my arm or explaining it to a child."

Cerrie Burnell

There was controversy when single parent Cerrie Burnell suddenly appeared on Britain's TV screens as a children's presenter for the BBC's CBeebies channel. Some parents objected to her appearance, or more precisely the fact that she lacked a right hand. They thought this would be upsetting for children. But the children didn't care and Cerrie has become popular figure, not only as a presenter but also as a children's author.

She discarded the prosthetic hand she wore as a child, went to drama school, and performed her own show at the Edinburgh Festival. Her dyslexia did not prevent her from doing much reading as a child, nor did it stop her producing a shelf of delightful children's books. As a single parent of a mixed-heritage child, she happily tackles problematic issues: 'Mermaid' tells the story of a girl in a wheelchair and 'Snowflake' is about a mixed-heritage child like her own daughter Amelie..

ii. Announcing the event

Send out press releases well in advance to explain what the event is about and why it is important to attend, for example to receive copies of a new report, or campaign materials, or to meet significant people. Also, ask journalists to tell you whether they are coming. Most will not, because they have so many other things to deal with. Call the ones you really want to attend and persuade them!

Don't just send press releases to the media. Other civil society organisations or public bodies may like to know what you are doing and may want to attend. This can make for a productive mix at the event and allow journalists to get quotes from other interested parties.

iii. On the day

Make sure you have press kits containing all the information you want journalists to take away, such as reports, speeches, stickers, notepads etc.

Make sure your platform is properly arranged. There should be water for speakers, in case they 'dry up'. Tables should be covered to the floor, to avoid unfortunate photos of people's legs.

Most important of all, table cloths, lecterns and backdrops should bear your organisation's logo or wording that helps to get your message across. These stand a better chance of staying in people's minds if they appear in film and photographs of the event.

iv. Following up the event

Compile a dossier of all the print, broadcast and online coverage you have received. It could come useful in later campaigns.

Thank those who gave you good coverage, and make use of it in future publicity materials. Correct those who got things wrong. Supply them with evidence to support your case.

Try to measure the impact of the press conference. How much coverage did you generate? How many calls have you received about the content? How many people asked for campaign materials? How many invitations to speak at other events did you receive?

Have a meeting with everyone involved to discuss the relative success or failure of the event. What lessons have you learnt for future occasions? Try to assess the real cost of the event, and whether this has been a wise use of funds in terms of impact, such as positive publicity gained, public education, and responses received by the organisation.

Pam Duncan-Glancy

UK Equality and Human Rights Activist and Scottish Labour Party parliamentary candidate in Glasgow North.

@glasgowpam

"The thing I've found most annoying about being disabled - the fact that society isn't ready for people like me."

Representation and responsibility

From a very young age, all my joints were badly damaged by Juvenile Chronic Arthritis. I was in and of hospital. For years my mum and dad felt like they'd slept on more fold-down beds in children's wards than they had in their own bed at home!

My Arthritis was pretty aggressive. By the age of five I was in a wheelchair. By my tenth birthday I couldn't stand up to get out of my chair and my arms were so stiff and stuck that I couldn't lift a cup to my mouth. My mum, dad, sister and friends helped me eat and drink, get ready, washed, and carried me – from my chair to my bed, to the toilet, to the couch, to a seat in restaurants and so on. We quickly became a family used to 'work arounds' in a society not quite ready for me.

That's the thing I've found most annoying about being disabled – the fact that society isn't ready for people like me. Not the pain, or the fact I look a bit different, or that I can't get myself dressed or take myself to the toilet. And it's the single thing that would make life easier for me and other disabled people – a society that was ready and willing to help us be part of it. One that recognises that disabled people's rights are human rights – and makes them a reality.

We've come a long way in the UK, but there are still many, many fights to have if we are to take our rightful place as equals. I wake up every morning with an overwhelming sense of impatience for this. An overwhelming sense of urgency for change. That's what fires my campaigning. It keeps me fighting. It keeps me going. That, and the fact that I believe in people enough to know we will win the fight for social justice. That's how I know we can have a better world for disabled people.

"Women make up half of the population, and 1 in 5 people are disabled. Yet still our Parliaments and council chambers look nothing like this."

The media have a huge role to play. Much prejudice is born from ignorance – disability discrimination is no different. The more we are part of this world, in the school, the workplace, in the bars, shops and restaurants with everyone else, the more people will begin to understand that we are part of this society too – and we can contribute to it.

Of course, there is no substitute for doing this in real life, but seeing other disabled people on TV is so powerful. I remember the first time I saw someone in a wheelchair in a TV soap opera. I was so excited. Then when I heard a disabled person commentating on current affairs on the news, and saw a wheelchair user in Parliament, I was inspired. Excitement and inspiration are good in and of themselves. As a young disabled woman growing up in the 80's, there weren't many people I could see 'like me'. But, that's not the main reason we need the media to take notice.

Disabled people make up 20% of the UK population. That's not an insignificant minority. We should be represented on TV, online, in our papers and on our radios too. And not just as 'the story' (all that 'inspiration porn'), but as the presenters, the actors, the pundits, the decision-makers, the reporters, and in the Boardroom too. Why? First, because we have a right to be equally represented. But, more importantly, because we can, and the world will be a better place when we can all see and use the potential in all of us. Disabled people are innovative by design, no one should miss out on that. The media included.

But I'm not only a disabled person. I'm a disabled woman. That's two things the media (and society) have trouble getting their head around. That's why I'm a lifelong disability rights activist and feminist, and why one of my proudest moments was to host two round table events on representation – one with the media, and one with

politicians. Both had disabled people in the room. I learned three things from those. First, we have a way to go! Second, people are willing to go there. And third, when we work together we can change together – being in the room made a difference. I guess I'd always thought that's the key. It's probably why I'm so passionate about representation – from the classroom to the Boardroom.

It's certainly one of the reasons why I stood in the unexpected UK General Election in 2017. I was the only woman standing for election in Glasgow North and the only wheelchair user standing for election in Scotland. Women make up half of the population, and 1 in 5 people are disabled. Yet still our Parliaments and council chambers look nothing like this.

The campaign was the most incredible, hard, and fun thing I've ever done, it was a true honour, and I was blown away at the strength of support for a wee woman in a wheelchair.

But I'd like to highlight one incident. Not because it set the tone – it didn't. The majority of the campaign was great. But, because the principle of it helps tell the story of why representation (including in the media – traditional and social) is so important.

I announced my candidacy in a video on social media, as many people do these days. #PickPam was my call to action. Fighting for equality and human rights, from the benches of Parliament, has been a near lifelong ambition for me. The moment I published that video, I was filled with pride. But it was only a matter of minutes for a troll (a man) to say "bit sick of Labour using the handicapped to get votes." Some faceless keyboard warrior who thought it was ok to write bile…but who wouldn't have the bottle to say it eyeball to eyeball.

I have a rule about stuff like this. In short, I ignore trolls. But this was different. This time I was standing for election. I wanted to win for Glasgow North, I wanted to win so that we can have a Government focused on public services, equality and human rights. But there was another reason I stood (and why I'm standing as the candidate again). I want to show other disabled women, across the UK, that they can, and should be heard.

As a disabled woman, I am often misunderstood and underestimated. Oppression, discrimination and inequality make that so. So, I wasn't surprised that my troll assumed I was being used by my party and that the only reason anyone would pick Pam would be out of pity. He'd underestimated me, but he wasn't going to misunderstand me. I replied: "1. The word you're looking for is 'disabled' and 2. I'm standing as the best person for the job, who happens to be a disabled woman."

As the only woman standing in Glasgow North and the only wheelchair user in the election, it was clear I was going to have to work doubly hard to prove my worth. I had a duty to stand up to him. And so, I broke my rule. In doing so, I set out my stall from the top – I'm a fighter. I stood in that election because Parliament needed – and still does – a different kind of MP and because Glasgow North needed a fighter.

*So, there you have it. Everyone should do their bit. But the media have a lot of power. Their **bit** should be bigger and they should use their power responsibly and openly. And I believe they will, because, they're people and they're people who want to tell other people's stories. And, we're people too. With stories to tell.*

That's why I will work my socks off to do my bit to change this world, one article and Parliamentary seat at a time. So, if you're a disabled person, tell your story. Write it. Film it. Most importantly, define it. And if you're in the media, share it. Reach out. Branch out. The world will be all the better for it."

"I'm a professional actor, dancer and model. I have Down's Syndrome but that is not all I am."

Sara Gordy, MBE

Sarah Gordy is the first person with Down's Syndrome to become a Member of the British Empire (MBE), an honour bestowed by the Queen for her services to the arts and people with disabilities.

Sarah says she first began acting in 1992 when she was only three. Since then she has appeared in numerous popular TV drama series, and in 2018 appeared on the West End stage in 'Jellyfish', a challenging love story.

Giving advice to disabled actors, she says, "It's not about disabilities but the person behind it as well and the same with Down's syndrome."

And she adds: "My industry has started to understand that diversity is an opportunity not a problem."

05

Advocacy and communication ethics

Members of the public increasingly rely on mass media for their information about human rights and health issues. It is vital that such information is accurate and reliable. This is a responsibility shared both by media professionals and those engaged in advocacy work for people with disabilities.

Sensitive issues require sensitive handling, and it can be difficult to persuade the media to take an interest in what some may see as a 'minority concern'. Inevitably some media coverage may be sensationalised or even simply inaccurate, especially when produced by journalists who are not 'experts in the field'.

Successful advocacy depends on reliable messages communicated clearly and effectively. If the intention is to achieve understanding and change by reaching the public via the media it is important for advocates to be confident, willing to challenge the media when they get things wrong, and able to answer questions with authority and evidence.

The following guidelines have been devised by the NGO MediaWise to help journalists deal with potentially problematic issues. These guidelines are a helpful reminder of some of the ethical considerations advocates and campaigners should take into account when communicating with the general public or with other journalists. They can also prove useful for CSOs wishing to operate ethically while advocating for groups that are sometimes misunderstood or misrepresented in the media.

1 **First, try to do no harm...**

This sums up the social responsibility of all good communicators. However, doing no harm does not mean pretending that everything is fine, or hiding unpalatable information. It is far better to share information about problems rather than try to hide them. You can help journalists to avoid perpetuating 'myths' about particular conditions, by supplying them with data, details and reliable contacts and expert sources.

2 **Get it right...**

Journalism is not supposed to be about spreading rumours, but about 'standing up' stories by checking the evidence. However, in the digital age of 24/7 'rolling news', the pressure is on to 'get the story first' which often leaves little time to verify information and increases the likelihood of making mistakes.

The consequences of such errors can be far-reaching, so it is important that advocates know what they are talking about, where to find accurate information, and how to counter 'scare stories' based on ignorance or misrepresentation. The media often get the blame for the confusion that arises when conflicting claims are made, for instance, by governments departments, rival organisations or hostile agencies. Trustworthy advocates have a vital role to play in drawing attention to the science, or to individuals with expertise who are best placed to challenge false claims.

Consistently supplying accurate information builds trust and establishes the advocate as a 'go-to' person for reliable information and quotes. Even sceptical journalists will tend to rely on such advocates to be telling the truth. The moment it becomes clear that they have been fed false or inadequate information, credibility is lost for all time.

3 Do not raise false hopes or promote 'fake news'...

Everyone is pleased to receive good news, but don't be tempted to over-simplify matters just because that's what journalists want. Complex matters need to be handled with special care.

Positive headlines may win friends and funding, but could have harmful consequences if they are not based in fact. It is far better to make absolutely clear the precise status of claims about new forms of treatment, equipment or even 'cures' than to allow journalists to perpetuate false information.

Few journalists are specialist enough to be able to distinguish between the conflicting claims of rival manufacturers about new equipment, medicines, or therapeutic techniques. Advocates and their clients have expertise and experience which can help journalists to understand the difference between 'good science' and unsubstantiated or over-optimistic claims.

If false claims are published, they should be challenged immediately. When making such challenges or assertions always supply evidence and sources to assist independent verification, and insist that equal prominence is given to corrections or clarifications.

4 Beware of vested interests...

Often, journalists will want to scrutinise the claims of campaigners in much the same way as they might scrutinise those of politicians or commercial companies. They will want to know who is funding a campaign and with what motive. These are perfectly legitimate questions. This is worth thinking about when seeking or accepting funds from those who may have an ulterior motive. How might a campaign be helped or hindered by being associated with a particular sponsor?

Journalists have an instinct for conflicts of interest. Always be willing to make clear where your funding has come from. If someone is benefiting commercially from involvement in your campaign that may become the story, detracting from the validity and overall message of the campaign.

5 Reject personal inducements...

Public trust in journalists depends upon evidence of their integrity – including independence from vested interests. Likewise, it is important for the integrity of advocates and their organisations not to be compromised. For example, there is nothing inherently corrupt

about a commercial company sponsoring a campaign but concealing that relationship may well generate distrust.

Readers, viewers and listeners form their own conclusions from what they read, see or hear. But, their views may change if they feel information has been influenced or is biased in some way.

It is not wise to seek favourable coverage by offering to pay for it, or to use the promise of advertising in return for positive stories. It is normal journalistic practice to clearly differentiate between editorial content and advertising.

6 Never disclose confidential sources...

This is a journalistic guarantee. Without such a commitment no-one would risk coming forward with information about wrong-doings that should be in the public domain. The European Court of Human Rights has upheld the protection of sources. In some places, journalists have gone to jail rather than reveal their sources.

If they did not honour this guarantee, why would anyone risk supplying important information in confidence to a journalist to help protect the public from misinformation, danger, and hypocrisy?

'Whistleblowing' should be regarded a public-service duty, but those who seek to warn the public about wrong-doings, for example in the running of an institution, need the protection of anonymity. Anyone supplying such information – which may be about dangerous or unethical practices in care homes or hospitals, for example – needs to be sure that the journalist knows the risks the whistle-blower is taking.

The journalist's job is to 'stand up' the story independently, in a way that ensures the information cannot be traced to its source. At the same item, it is vital to be able to provide evidence for your claims when disclosing details of a scandal to a journalist, so that it is easier for them to check – so long as you do not compromise yourself in supplying extra information to which only you have access.

7 Respect privacy

Few people would choose to live a life stigmatised by social exclusion or pain. Yet disabilities and lifelong illness fascinates those who are neither ill nor live with a disability. The media can play an important role in bridging the gap between them, but there is a constant risk of prurience or disrespect.

When running a campaign highlighting abuses or neglect of human rights, for example, advocates should seek to ensure that there are individuals who are willing and properly prepared to talk to journalists. If journalists are left to find their own interviewees, there

is always a risk that the spotlight will be put on people who are unused to publicity and its consequences, or who do not fully understand the issue.

When a story breaks, journalists often seek out suitable 'case studies' at short notice. This can be annoying, time-consuming and potentially problematic for advocacy organisations, so it is far better to be well prepared. Especially when an organisation is seeking publicity for a particular issue, it should provide training and support for potential interviewees. There is a 'duty of care' both to those whose circumstances are being highlighted, and to the media professionals whose services you wish to cultivate.

Plan ahead. Collect 'case studies', but obscure people's identities when supplying examples to the media. Make sure those who are willing to be interviewed know that they can decide whether or not to make public their full identities. Remember journalists have the right to ask anyone any questions, but everyone has an equal right not to answer them.

8 **Be mindful of consequences...**

In the rush for stories, often, little thought is given to the potential consequences of 'going public'.

The stigmas associated with a variety of disabilities and conditions can be very problematic for individuals and their families. Advocates must be especially mindful of this and forewarn journalists accordingly. It is perfectly alright to ask that the media use an assumed name, and even use an actor's voice to obscure identities, if there is good reason for obscuring the identity and/or body features of an interviewee.

Never introduce journalists to people who have not given their consent to being interviewed or photographed in advance. News is often about the unusual, and the more unusual or strange something may seem, the more risk there is that it will be sensationalised by the media.

Ideally the subject of a story should be willing to appear openly, as that is the best way to confront and challenge prejudice. However, that is it not always practicable. It is important to ensure that the most vulnerable people in society appreciate the risks and agree the conditions under which they are prepared to go ahead. And sometimes, it might be necessary to obscure the identity and/or body features of an interviewee as mentioned above.

When people do agree to tell their story as part of a campaign, talk through the potential consequences and make sure they are prepared for the questions they might get asked.

9 **Never intrude on private grief…**

Death is the most private thing, although it may take place in the most public circumstances. It is important that the media report about unusual deaths and disasters, but they cannot know before making an approach whether the bereaved will welcome such attention or find it intrusive and objectionable. This is where advocacy groups can help journalists by acting as intermediaries with the bereaved.

While some welcome interest in their loss, others may be too upset to make a considered decision about expressing their grief in public. They may rely upon others to advise them on how to respond to media interest. This applies especially when dealing with, for example, suicide, accidents or crimes involving people with disabilities.

10 **If in doubt, leave it out.**

The 24/7 'rolling news' agenda has given rise to speculative stories - second guessing what is about to happen. However legitimate it may be to report about speculation, provided it is clearly presented as such, it is far better if 'news' is based on verified facts. Speculation can lead to rumour and the fabrication of 'facts'. Making things up is what has given us 'fake news'.

Never make false claims to journalists or allow them to leave with an 'impression' where there are no facts to substantiate it. It is far better to explain that there is doubt or controversy, and to encourage them to make this uncertainty clear, rather than risk potentially miniforming the public.

11 **And don't forget personal integrity…**

Those working as advocates in the fields of disability, whether or not they themselves are disabled, have a duty to operate with the utmost integrity. Their organisations should ensure that they have a Code of Conduct as part of their terms of reference or contract of employment which determines how they should fulfil their function. This helps to preserve the integrity of the organisation as well as to ensure that media relations are conducted in a fair, honest and transparent way.

Guidelines for working in public relations and information services

Based on Public Relations Codes in the UK and Ireland

1. In performing their duties, public relations and information officers should observe the highest professional and ethical standards of integrity, confidentiality, financial propriety and personal conduct.

2. They should defend the freedom of the press and the right of the public to balanced and reliable information at all times.

3. They should deal fairly and honestly with the public, their employers or clients and colleagues in the media.

4. They have a duty to ensure that their employers and/or clients acknowledge that goodwill and reputation are based on trust, and that effective public-relations practice depends on enhancing the organisation's reputation by truthful means and by ensuring that information disseminated is accurate and fair.

5. They should refuse to disseminate false or misleading information and should take care to avoid doing so inadvertently.

6. They should not engage in any practice likely to corrupt the integrity of the public relations profession, the organisations they represent, or the media. As a consequence, they should be prepared to disclose actual or potential conflicts of interest.

7. They should not seek to 'buy' editorial space or air time, either by direct bribery or by promising to buy advertising space. Hospitality should not exceed normal courtesy. When producing material for 'advertorials' or advertising features, they should insist that the material is clearly identified for what it is.

8. They should provide independent professional advice to their employers or clients without fear or favour. Whether it is accepted or not, they should be willing to explain and defend decisions by the organisations they represent in truthful terms.

9 Those working for local, national or federal government bodies should maintain professional political neutrality at work, unless their conditions of employment specifically allow otherwise.

10 Political considerations should not be an excuse for altering or modifying technical information when it is communicated to the public.

11 They should seek to enhance their skills through training and by keeping abreast of developments in their respective disciplines.

Neringa Jurciukonyte

Director, Lithuanian National institute for Social Integration/ Media4Change

"These 'readings' demolish barriers of uncertainty and fear and develop understanding. Readers often leave thoughtful, positive and energised, and quite often become friends with their new-found 'books."

The Human Library Experience

The 'Human Library' is a method of informal education that encourages social awareness, tolerance and respect for human rights. It brings together 'books', 'librarians' and 'readers'.

The 'books' are actual people from different social groups who experience discrimination or social stereotyping, who have a lot to say about social inequality, and are willing to answer deep and often intimate questions about their life and the lives of people like them.

The 'librarians' greet each 'reader' - who may be a passer-by, an invited guest or targeted audience - who comes to the Human Library. Librarians are trained volunteers responsible for preparing guests for the reading process, explaining the rules and inviting them to choose a book from the catalogue.

New readers are often nervous. What will I ask the book? Will they feel ok about my questions? Will I offend the book?

One reader explains, "before talking to a 'trans book', I hesitated: I don't know any trans people. What will we talk about? And after seeing the 'book's' friendly smile, I managed to start a nice conversation – I'm glad I decided to come to the event."

The process of 'reading' involves a sincere conversation between the book and the reader, getting straight answers to genuine questions. It becomes a comfortable and intimate interaction lasting 15 to 25 minutes between people from different social groups. Librarians observe these conversations, but only intervene if they deem it appropriate.

These 'readings' demolish barriers of uncertainty and fear, developing understanding in their palce. Readers often leave thoughtful, positive and energised. Quite often, they become friends with their new-found 'books'.

The concept of 'Menneskebiblioteket' was the brainchild of Danish brothers Ronni and Dany Abergel in 2000. It was further developed in Lithuania in 2007 as a part of the Council of Europe campaign 'All different – all equal'. Since then the 'Human Library' became an important informal educational technique all over the world.

We have organised Human Libraries in schools (to challenge bullying) and in the Lithuanian parliament too. It is an ideal way to get politicians to engage directly with people whose voices are seldom heard.

It is also important to avoid the risk of generalisation and new stereotypes. When we organise a Human Library session, we always try to invite the same people to come again and "read another book" from the same social group as before just to show that even people from the same social group may see things differently.

The 'Human Library' movement has been a big inspiration for us. It has helped us to see 'reality' from many different perspectives and provided us with a great source of ideas for promoting social integration. It also gave rise to our Social Taxi service which allows people with disabilities to become more mobile and independent in planning their daily activities.

Properly equipped, comfortable vehicles driven by personal assistants trained in first aid, communication and other skills, deliver clients safely to and from shopping and cultural trips and public and medical appointments. Devised, planned and implemented with theinvolvement of disabled people, the service operates in four Lithuanian cities and is expanding.

http://humanlibrary.org/about-the-human-library/
https://www.aukok.lt/projects/Social-Taxi
http://www.negalia.lt/en/keeping-the-wheels-on-lithuanias-taxi-service-for-the-disabled/

06

Disability online

The starting point for any CSOs these days should be creating a website which establishes its credentials and provides a base from which to attract attention, supply information, build contacts and promote activities.

'Brand image' and accessibility will be the key determinants of the success of a website. So, plan carefully, test your proposed 'architecture' and make sure your web designer really understands your needs and those of your target users. Will you need sound? What size should your print be? Have you considered issues such as appropriate colours?
See: https://www.usability.gov/get-involved/blog/2010/02/color-blindness.html

When creating a website consider using RSS (Rich Site Summary) feeds to alert your supporters to any changes in site content, and to flag up your latest newsletter.

You should consider including social media links – such as Facebook, Twitter, Instagram, Skype, etc – to make your website more interactive and drive engagement through social media. While websites can suffer from a lack of traffic, social media are a more dynamic way to engage with new users.

About one third of Macedonian citizens, more among under-25s, are active on social media platforms. They tend to use these as their main channel for interpersonal communication, which makes social media a useful resource for organisations who want to engage with their audience in an innovative way.

The 10 most popular social networks are:

1 **Facebook**	2 **Google**	3 **YouTube**	4 **Twitter**	5 **LinkedIn**
6 **Erepublik**	7 **Flickr**	8 **Deviant Art**	9 **MySpace**	10 **Badoo**

(Not forgetting **Top.mk** and **Instagram**)

Unfortunately, Macedonia has also earned itself a reputation as a hub for 'fake news' with enterprising youngsters launching political news sites promoting dubious 'clickbait' material to win visitors, especially from the USA, in order to attract advertising revenue.

This could make ventures into the social mediasphere problematic for NGOs wishing to draw attention to disability rights, especially given the Law on Civil Liability for Insult and Defamation introduced in 2012.

Social media are a cheaper and more effective means of mobilising targeted groups to take part in campaigns and demonstrations. Well-designed leaflets, posters and banners can be distributed nationally online for local reproduction and distribution.

When using social media for campaigns it is vital to plan carefully and make informed decisions about which platforms best suit your purpose. It is equally important to understand what are the advantages of social media (if any) compared to 'traditional media', and whether your marketing strategy should combine both and how.

In terms of cost, social media tends to be much more effective. Designing, printing and distributing a print advertisement is much more expensive than sending an email, having an online advert, or displaying a banner online. It is also easier to modify a post online if there is a need for alteration. Leaflets or brochures are costlier to reprint and redistribute.

NGOs with small budgets need to be imaginative about the way they use their resources. For example, judicious use of radio – current affairs and phone-in programmes – linked to an online presence can be very effective.

Social media provide ideal opportunities for interactive communications – reaching out to people, especially those who may not appear in public often, starting conversations, and collecting data. However social media can also generate negative responses, trolling and hate speech. Once contact has been made with particular target audiences (those with very specific impairments, for example) it may be better to create a private social media group.

Having chosen who to follow on Twitter, **Tweetdeck.twitter.com** provides an instantly updated dashboard of communications by selected users. **Buffer.com** can help manage social media accounts to ensure that you can schedule messages appropriate to selected audiences. Another way of monitoring impact is to use **Bitly.com** which can show how many people have clicked on your material and what platforms they used to access your material. This intelligence may help you to decide which platforms are most effective for your purposes.

Once social media outlets are receiving significant numbers of visitors (clicks) they can be a means of fund-raising using automated advertising networks like: **https://www.google.co.uk/adsense/**. This can bring its own set of problems, however, since the algorithms directing advertising to your site will relate to your content and language, sometimes with inconvenient or distinctly inappropriate results. The outcome needs to be monitored carefully, especially if there is a risk of alienating supporters…

It is vital to constantly monitor possible connections online. For example, you should thank those who follow you on Twitter and follow them back where appropriate. Seek out journalists, other media professionals, academics and politicians who have taken an interest in your field. When an opportunity, such as an event or publication of research, arises make a point of inviting your followers to meet face to face or be a part of the event.

Managing your social media could become an important element in your campaign work. This can be tiresome and time consuming, but several programmes exist that can assist you in this task.

Social Sprout is one online resource you can use which links up people and issues internationally across social media platforms. Crucially, Social Sprout seems committed to inclusivity. **<https://sproutsocial.com>**

Hootsuite is another programme that curates content across platforms. **<https://hootsuite.com>**

A more sophisticated method of tracking content, videos, images and posts on Instagram, Snapchat and other platforms is through a monthly subscription to Spike **<https://www.news-whip.com/newswhip-spike/>**

Google Alerts monitors the web for new content which might be of interest. **<https://www.google.com/alerts>**

Reddit calls itself the 'front page of the internet' collating material based on themes. **<https://www.reddit.com>**

Online petitions and email campaigns are a popular form of online campaigns, which can be created through websites like **https://mailchimp.com**; **Avaaz**, a U.S.-based online site that promotes global activism; **Change.org**, another online-petition website; or **38 Degrees**, a UK not-for-profit political-activism organisation.

Knowing how to target your online media campaigns to capture the biggest audience is important.

For example, protesters in Poland demanded that the government increase disability benefits to equal the national minimum monthly unemployment benefit, with more for disabled adults who cannot care for themselves. They asked the state to support children with disabilities once they reach the age of 18, if they are unable to live independently. Their protests were reported far and wide, from local newspapers to The Washington Post. **<http://thenews.pl/1/9/Artykul/361520,Polish-Ombudsman-wants-disabled-community-and-govt-to-agree-amid-protest>** The tactics of the Polish government were also reported.

Adam Pearson

Actor, campaigner and presenter

He developed non-hereditary neurofibromatosis from the age of five. Now, he is active in challenging bullying associated with deformities.

Who gets to play disabled people on UK TV?

https://www.theguardian.com/commentisfree/2018/sep/02/disabled-actors-bbc-elephant-man-normalised-exclusion?CMP=Share_iOSApp_Other

Mothers of disabled children joined in to get their voices heard. **<https://oko.press/3-things-you-need-to-know-about-the-protest-people-with-disabilities-and-their-carers-in-poland/>**

Newspaper articles and visibility on broadcast media remain essential as ways of achieving a public presence. Consistency in terms of both branding/image and message are crucial to effective campaigning.

Perhaps, the most important strategy is for you to be in direct contact with media professionals. This contact may begin online but should quickly turn to offline interactions, such as inviting journalists to events, and feeding them stories. Even though social media tops the list of tactics, in-person events are rated as the most effective way of reaching your target. It is important to build a database of good contacts and customise your news releases rather than using a scatter-gun approach and hoping for the best.

Finally, here is a video in which people with disabilities challenge the prejudices others have about their sexuality and reproductive rights.
https://www.youtube.com/watch?v=4Dxhd139oVE

Liz Crow
Artist-Activist

"The private part of most disabled people's lives is invisible"

Taking what is hidden into the public sphere

Performance artist Liz Crow is used to taking people by surprise, even when she's lying exhausted in bed.

She once sat on her wheelchair dressed in Nazi uniform high on a plinth in London's Trafalgar Square.

On several occasions, she has moved her bed into public places and invited strangers to sit with her and talk.

When the UK government brought in a major welfare benefits overhaul that led to increasing poverty and hate crime, Liz realised that the private part of most disabled people's lives was invisible. In her 'Bedding Out' performance, she

decided to take the private life and put it into a public space, inviting people to join in conversations about the work and its politics. The work took place in several museums and galleries, as well as being live-streamed via social media.

"I was joined by people completely new to the issues and others who were on the sharpest end of austerity," she says, "and I was amazed at how profound some of the conversations were."

Liz runs Roaring Girl Productions, working through a variety of media forms to combine high quality creative work with practical activism.

Her award winning film 'Frida Kahlo's Corset' offers a rare perspective on the work of the celebrated Mexican artist Frida Kahlo, who wore orthopaedic corsets because of an impairment and painted them as a declaration of identity.

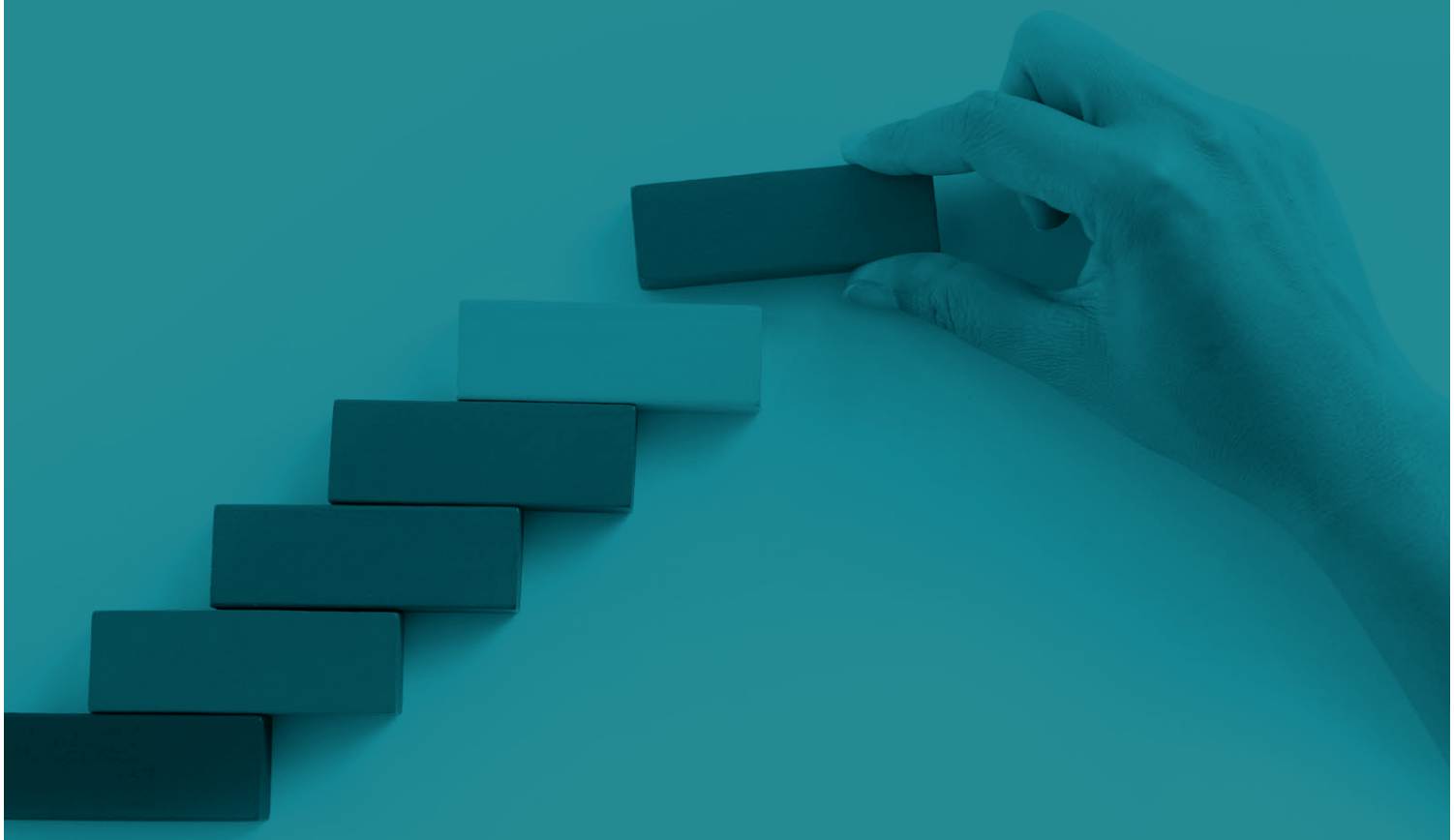
Another of her projects, 'Resistance', commemorated the 70th anniversary of the Nazi programme of mass-murder targeted at disabled people, looking both at this hidden history and the messages it holds for today. The project included a film set in a sanatorium for disabled people from which the inmates will be transported to their deaths, and tells the story of one woman's attempt to escape.

In one of her most challenging projects, 'Figures', Liz gathered half a ton of river mud by hand and spent 11 days and nights at low tide on the foreshore of the River Thames in the middle of London, sculpting 650 tiny human figures. Each one of them represented a constituency of Britain's Parliament and had a different but real story to tell about the impact of austerity. She toured with the figures, then returned home to Bristol to fire them in a riverside bonfire, before grinding them to dust and scattering them in international waters as a symbolic call for the world to see what was happening in the UK.

www.roaring-girl.com

07

Campaigning



A. campaign planning

To be effective campaigns have to capture the popular imagination. This means that campaigners have to be imaginative, persistent and have a persuasive argument, or a lot of money! But even expensive advertising campaigns can fail.

Earnest campaigners often think that the media will, indeed should, make their campaign successful. It's not the job of journalists to make your campaign effective. Just because YOU decide to run a campaign doesn't make it NEWSWORTHY. It is your job to keep finding new ways of demonstrating the importance of your messages to the public and influencers. Those with lots of money can saturate society with leaflets, posters, multi-media advertising, and even hire public relations companies to promote their message. It is not so easy when resources are scarce.

HOW you go about your campaign and WHO you use to communicate your messages may be the hooks media professionals need to make it newsworthy.

Think about significant **anniversaries** which might offer the media a hook on which to hang stories in support of your cause (See Chapter 8 for examples). Plan in advance. Do the research for the media. And, make sure there are historic or contemporary anecdotes which illustrate your message.

Civil disobedience can catch the attention of the media, politicians – and the police. You need to employ careful thought and planning to ensure that no-one is put at excessive risk and that the right message and positive coverage is achieved. Consider what policy changes might result from this event, if any.

Demonstrations are one form of showing support or opposition to particular policies. As they are not unusual phenomena, put some thought into what would make your demonstration different – colourful fancy dress, music, witty placards – anything that will give the media pictures. Perhaps, medical staff, injured soldiers or sportspeople are willing to show support by turning out in uniform. Or, perhaps, there is a theatrical or other artistic event that has some relevance and the cast will appear in costume. Or, even, there are celebrities willing to lead the demonstration.

Make use of **social media networks** to keep supporters informed and to organise events.

Images can be worth a thousand words. Modern cultures are visually sophisticated, and media are drawn to strong images – whether a powerful photo, or a vivid description of an event. Clear colourful visualisations of key data may give media useful background information. You should also take note of visual aspects of interview backgrounds, your own campaign materials, and media stunts. Stark protective clothing, morbid imagery or a carnival feel may be appropriate at different times. Likewise, creative props are likely to draw the cameras.

Social media also come alive with the addition of images, infographics, YouTube excerpts, memes, etc.

Interviews may give your organisation access to literally millions of people, but are seldom prepared with the care given to other presentations. There are two basic types of interview:

1. **Unexpected request for comment.** In this case, offer to call back, in say 10 minutes, and take time to review key points and facts.

2. **Pre-recorded and live broadcasts.** Similar guidelines apply. Find out about the programme, the length of your slot, and typical audience. Might someone else do this onebetter? Plan key messages and stick to them, but sound natural and human. Two main themes are often enough – if possible check key points from an index card or single sheet.

Spokespeople present the human face of your argument. Ideally a spokesperson should be clear, credible and interesting - bear in mind that people take more note of voice and body language than actual content. Different media situations also call for different 'front' people. The most senior person may not be suitable - careful handling required.

Social media posts, email and telephone **'trees'** are a quick way of alerting supporters to a current action. Telephone 'trees' work by each person contacting five more so the message quickly cascades. Everyone who has been contacted will ideally take up the challenge immediately by contacting their political representative, going out into the street and making some noise, or any other action that has been planned. The same technique can be used to create a 'flash mob'. E-mail can also be used this way, but it rarely achieves immediate results.

Websites can be a valuable way of building membership and raising funds. Always link your organisation's Twitter and Facebook posts on your website and vice versa, to generate traffic. Remember that social media posts are a good way to direct your followers to more detailed information on your website.

Build websites that provide clear information, without using 'jargon' and keep them updated regularly. Provide Factsheet and/or answers to Frequently Asked Questions (FAQs) and use them to challenge myths about disabilities.

What makes a campaign newsworthy?

Usually, a campaign becomes newsworthy when it is unusual, amusing, or even shocking. Think whether your campaign is bringing something that is rarely heard or seen into the public domain.

Is there something genuinely NEW about the message you are trying to communicate?
For instance, is it based upon new scientific information? A recent discovery about a particular group of people? Or something that could have far-reaching consequences for the wider community?

Are you trying to influence policy making?
If your campaign is about developing new public policies that will have a positive impact on people's lives, you need to think it through very carefully. Are you clear on your aims? Have you collected sufficient evidence and research to inform decision-makers? Have you tested out your ideas on the people mostly likely to be affected? Are you confident that you can answer objections to changing relevant existing policies? Can you suggest ways of measuring the impact of these changes?

Is your campaign taking some unusual form?
For instance, are you asking people who support you to do something or wear something distinctive? Coloured ribbons and armbands have proved effective in the past, as signifiers of support and/or a means of fund-raising. If you have the resources think of something striking that people in the public eye can wear or carry – T-shirts, hats, scarves or shopping bags – that will immediately associate them with your message. First of all, however, you need to establish the identity of your chosen emblems. It may be that a single colour or combinations of colours will do the trick.

Below are some examples of clever techniques to gain attention:

Wooly Hat Day to help the homeless
https://www.mungos.org/get-involved/fundraise-for-us/woolly-hat-day/

Red Nose Day for Comic Relief
https://www.justgiving.com/campaigns/charity/rednoseday/rednoseday2017

Unusual 'selfies' as in 'No make Up Selfies'
https://blog.justgiving.com/what-can-we-learn-from-nomakeupselfie/

Make a colour your own, as in
http://www.pinkribbonfoundation.org.uk/support-us-2/
https://www.nat.org.uk\
https://shop.alzheimers.org.uk/Memory%20Walk/Memory%20Walk%20Wristband%20-%20Green

There are some other ideas here
https://blog.justgiving.com/category/case-studies/

For fundraising ideas, see
https://blog.udemy.com/non-profit-fundraising-ideas/

Is there a celebrity willing to help launch or lead your campaign?
Find celrbtities who have a personal connection to your campaign, someone willing to admit to a particular disability, for instance, or someone with a disabled relative. They will need a suitable personality, skills and a positive image that will enhance your campaign message. Choose carefully and think about any image problems that the celebrity might have. Comedians and pop stars may have the right profile, but not if they have a habit of telling tasteless or offensive jokes, have a history of infidelity or substance abuse.

Is there something visually exciting about the campaign or its launch?
If you want TV coverage you must make sure you have striking visuals to offer, in which case the media will want pictures too. Devise a good 'photo-opportunity' – release lots of colourful balloons, organise a fancy-dress mini-marathon, get the Mayor to do a bunjee jump, or get a well-known celebrity to autograph a gigantic banner...

No problems?
Behind every good idea there is a potential disaster waiting to happen — as the media know only too well. Don't take too many risks. Plan carefully and consider all envetualities…

Make sure that no-one can get hurt by one of your 'stunts'. Don't let people, including the media, have too much alcohol at your cocktail party. And, ensure everyone knows exactly what they are supposed to do and say on the day!

How much can you afford to spend, and where is the money coming from?
Think very carefully about your budget. A campaign can fail if you suddenly run out of money to complete it midway. Devise a detailed budget that takes everything into account – printing, travel, extra staff, telephone and postage costs. Always be clear about where you are getting your funds from. You should know what your funders want from you to justify their investment. Are there conflicts of interests here that might damage your image?

Do you have the right people to make the campaign work?
Campaigns depend not only on staff but also on volunteers – to hand out leaflets, or take part in publicity stunts, etc. You may also need experts who can back up your message with reliable facts and figures. It is no good launching a campaign when key experts will not be available. Check their work schedules and holiday plans beforehand!

Have you thought about follow-up activities?
A successful campaign will generate interest, requests for help and more information packs, especially if you manage to get good media coverage. Have you made arrangements for someone to handle telephone enquiries? Have you prepared enough information packs to meet anticipated demand? Do you have a contingency plan so that nothing is wasted if the calls do not come? You might consider running a mini-campaign to deliver materials to schools or colleges or workplaces at a later date. And, how will you measure the success of the campaign? Will you conduct follow-up surveys to discover how well the messages have embedded or how useful people found the information you distributed?

A good starting point for any campaign is an authoritative, if not legally binding, commitment which the government has acknowledged.

The UN Convention on the Rights of Persons with Disabilities provides such a starting point for a campaign.

Be prepared

All of the above requires careful planning and the first question must be:

What do we hope to achieve?
Make sure you have a clear answer that everyone connected with the campaign understands.

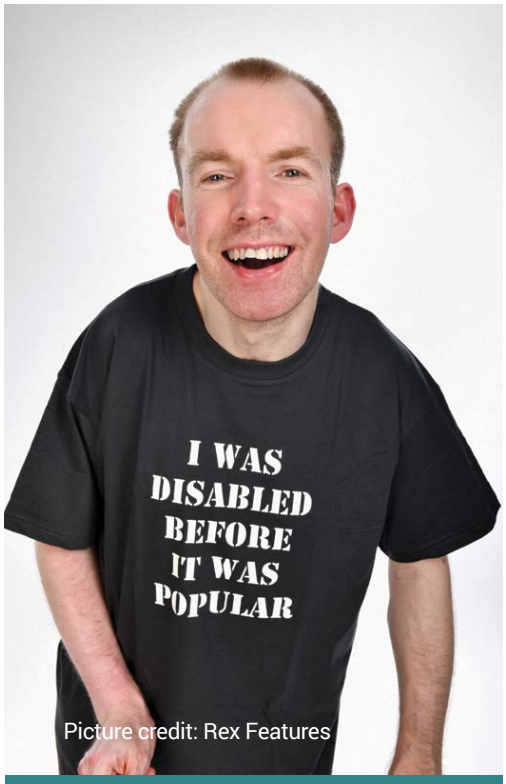
If you want to use a slogan to get your message across, don't be too 'clever' about it. You probably know a lot more that the people you are trying to influence, so think about how they will understand your slogan, from their point of view. There are many different ways of expressing a simple message, and many ways of receiving it. Even, who the message is coming from may determine people's reaction to it.

How are we going to achieve it?
To a large extent, your answer will depend upon the human and financial resources at your disposal. By making best use of limited resources some campaigns can be very effective without being too costly.

For instance, students love 'stunts'. Fifty to one hundred people can make an impressive and photogenic crowd if they all turn up outside a well-known location wearing the same colour clothes or carrying the same posters or releasing helium filled balloons for a photo-opportunity – especially if you can give added significance to the numbers, for example 50 deaths on the roads in one week, or a hundred new hospital beds needed in the region.

'Flash-mobs', singers, dancer or musicians in key locations can win lots of publicity, provided the media are properly primed, and be shared via YouTube, Instagram and other social media.

Petitions and letter-writing campaigns – addressed to the media, politicians, companies or other institutions relevant to your campaign – can be a useful technique, serving several purposes at once.



Picture credit: Rex Features

Lee Ridley

Britain's Got Talent 2018 Winner

Disabled since childhood and unable to speak, Lee uses a communication aid in his comedy routines, performing under the stage name Lost Voice Guy.

He has gone on tour since winning the popular vote prize of £250,000 on *Britain's Got Talent*. He also had an opportunity to perform in front of the British Royal Family.

First draft a basic letter to express your purpose. Keep it simple and allow people who agree to sign it to add their particular concerns to the letter. Get your supporters to send them in as their contribution to the campaign. By doing this you can make people think not just about the issue at hand but also about the value of getting involved.

The very fact that lots of people are writing and sending similar letters - by snail mail - could be newsworthy in itself. If you decide to use emails instead, then when public figures receive lots of emails from different people, campaigning about the same issue, they start to feel the pressure and are more likely to respond positively to the campaign.

If your letter gets published in the press, organise people to respond, supporting or even challenging your point of view. This is a great way to build engagement and may persuade editors to look into the issues – and become advocates in their own right.

What are you going to do with the interest you have aroused?
The campaign itself is just part of a process which began with your preparation and hopefully will never come to a full stop. Having highlighted an issue, it is important that you are able to move forward with the interest it has generated in order to affect social attitudes.

You should have a development plan in place in order to make best-use of the information and contacts you have obtained.

How are you going to measure effectiveness?
You need to have some means of evaluating your campaign. This is one of the best ways of persuading funders that your efforts are worthwhile.

Allocate adequate time and resources to allow you to measure the relative success or failure of your effort. You should use lessons from one campaign to inform your next one.

Campaigns require investment in scarce human and financial resources, so it is important to measure the value of such investment, in terms of money, time, and impact. To discover whether your investment has been wise and effective, you need to measure your campaign against clearly defined objectives set at the outset (qualitative analysis).

There are sophisticated methods for evaluating public relations campaigns, but some techniques are more sensible and cost-effective than others.

Simply measuring the number of column centimetres devoted to your campaign in print publications (quantitative analysis) is one indicator of impact. It may provide impressive figures, but they don't mean much if you do not know what type of publications were measured. What is their circulation? Who are their target audience? Are these publications read by the people

you want to contact? What about their online presence? And the effectiveness of their use of search engine optimisation (SEO)?

Qualitative analysis yields more useful data but can be more time-consuming (and expensive) to gather. By engaging an agency (or a university department) to analyse your media coverage, you will ensure you know what systems of measurement are used. Are they treating all types of publication/programme alike?

If they are, coverage in a small circulation specialist journal may be 'weighted' the same as for a mass circulation newspaper. This could distort your perception of how effective the campaign has been. However, a specialist journal aimed at the right target group may reach more of your target group than a national newspaper.

Today, you should also take into account the 'multiplier effect' of social media (also see Chapter 6). Referring people to articles and programmes, and using hashtags and links to share information adds value and opens up new avenues for interactive communication.

B. EVALUATION

It is also vital to know what actual messages the coverage is communicating. Not all coverage is effective coverage. Measuring column centimetres will not tell you whether the coverage was negative (critical) or positive. In countries where the PR profession is highly developed, agencies use systems to measure the relative strength of positive or negative messages.

You will want to see how much of your intended message came through in media coverage. It may be possible to calculate how many of your target audience will have received the message by analysing the demographics of the relevant outlet's audiences.

In financial terms, editorial coverage is worth as much as three times more than a paid-for advertisement carried in the same publication, because readers seem to give greater credibility to editorial content than adverts. The more editorial coverage a campaign attracts the greater its 'value for money', whether measured against actual expenditure or staff time. In addition, you can 'recycle' print or broadcast editorial coverage via social media to influence new audiences.

Imagine your campaign as a pebble thrown into the pool of public discourse. How big are the ripples it has caused? How far have they extended.

The best advice in evaluation exercises is: keep it simple, and keep it common sense.

Some of the measures you might consider are:

How much did you spend?
Look at the budget and itemise everything, including staff hours. Keep an eye on hidden costs, such as the extra telephone time/travel or reprinting costs needed to respond when you get inquiries — this can continue for a long time after the campaign launch.

Do not only look at external factors when you evaluate.
Bring the campaign team together for a 'debriefing'. Talk about the efforts they put in. Did people have to work late to get the materials ready? Were there extra costs which you did not expect? Did telephone inquiries increase so quickly that you did not have enough staff — or enough telephone lines? Write up a short report based on the information you gather. You can use it to inform the planning stage of your next campaign.

Try to measure public awareness of the issues before and after a campaign.
This can be very expensive, so try to do it cheaply. Perhaps you could persuade a newspaper to run a readers' poll about your main message. Give them some exclusive part of your campaign, and get them to run the poll again in the days after the launch. Or try and get a polling agency to add some questions to one of its regular public opinion polls – this can be cost-effective if you have invested a lot in a campaign.

Maisie Sly

Actor, star of 'The Silent Child'

Maisie Sly is profoundly deaf. In her first outing as a 6 year old British actor she appeared in the OSCAR winning film The Silent Child, and won Best Actress at The Hollywood International Moving Picture Film Festival and at the Rhode Island International Film Festival in the US.

Since then she has charmed TV audiences with her appearance in an advertisement for fish fingers, as part of Aldi's contribution to Deaf Awareness Week at the time. The advert features sign language and is completely silent until the final frame and Maisie's captivating laugh.

Examine what others in your field are doing.
Share your experiences with other campaigners on disability issues, and see what their experiences can teach you. Look at the strength of their messages and their arguments. What can you adopt or adapt for your next campaign?

Were you able to implement your 'follow on' strategy?
If someone made contact with you after hearing about your campaign on TV, in a radio programme or online, were you able to answer their questions, provide them with accessible information or refer them to appropriate authorities? Did you log these inquiries? Did you ask these people if they would like to stay on you mailing list or become more active volunteers?

Have you found out what your target audience thought about the campaign and your information packs?
Follow up the people who called you for information a few weeks later, ask them what made them call you and what they thought of the information you sent them. What positive action have they taken as a result? Make a note of their replies and use them in future campaigns, or to inform your planning. Get a 'focus group' of people to give you feedback. What did they think about the look of your materials? How about the messages in them? Were they easy to find?

Did your top spokesperson increase their profile as a result of your campaign?
This may well be an objective for you, so find ways to measure this. Was your top spokesperson interviewed on the main national radio and television news bulletins? Did they appear on a 'flagship' current affairs programme during the campaign week, or soon after? As part of you follow up you might want to 'place' a profile of the top spokesperson in a popular magazine or get them invited to speak at an important conference to ensure the 'message' keeps getting out.

Evaluating successful campaigning

- Did you get 'value for money'?
- Is there evidence that the public is more aware of the issues than before?
- Did it generate hostile responses? What were they and how well did you counter them?
- What difference has the campaign made to social attitudes?
- How did your target group/s respond to you information materials?
- Do key figures in the campaign have a higher public profile than before?
- Have you publicised evidence of your success?
- Have you implemented your 'follow-on' strategy?

08

Reporting and representing people with disabilities

Some thoughts to share with journalist contacts

People with disabilities have as much right to a voice as anyone else. These notes are based on advice received from disability groups, disabled media professionals, and journalists who cover disability issues.

For those who need an 'angle' to publish stories about disabled people, there are plenty of international 'days' which provide an opportunity.

January	
4	World Braille Day www.bvcil.org/2013/01/04/world-braille-day-friday-january-4-2013
27	Holocaust Memorial Day www.hmd.org.uk
March	
Mid-March	World Glaucoma Week www.wgweek.net
21	World Down Syndrome Day www.worlddownsyndromeday.org
September	
Last week	International Week of the Deaf www.wfdeaf.org/about/international-week-of-the-deaf
October	
2nd Thursday	World Sight Day http://www.iapb.org/wsd14
15	International White Cane Safety Day www.lionsclubs.org/EN/our-work/sight-programs/vision- events/white-cane-safety-day.php
20	International Day of Hope & Remembrance for Those Affected by Hate Crimes www.172430notohatecrime.wordpress.com/projects/international-day-of-hope-and-remembrance
November	
13	World Kindness Day www.kindness.com.au/world-kindness-day.html
December	
3	International Day of People with Disability www.idpwd.com.au

Of course, this is by no means an exclusive list. The MediaWise Diversity Calendar[1] offers many other events to which human-interest stories can be attached.

People with disability deserve to have their narratives and stories heard just as much as non-disabled people. Narratives about disability can transform the lack of diversity in the media.

One of the most effective ways of challenging prejudice and misconceptions, and changing social attitudes is to incorporate their stories within popular culture, especially television dramas and soaps.

Advocacy groups can help media creatives to develop such inclusive narratives, and to ensure that disability is not merely incidental to the story but intrinsic if not central.

People with disabilities are PEOPLE first, so the focus should be on the person first and the disability only to the extent that it may be directly relevant. Focusing on the person emphasises what we all have in common rather than our differences.

The Social Model of disability provides many opportunities for the media to cover issues faced by people with disability. It refers to the notion that people are disabled by the fact that our cities, institutions, buildings, transport, technology, workplaces and other spaces are designed on the assumption that their users are physically fit, healthy, hearing and sighted adults. In consequence, those who do not fit this 'norm' are hampered by built-in 'design faults'. A wheelchair user cannot easily manoeuvre stairs, but a slope or ramp is unlikely to deter a physically fit adult or child. If signs can be printed, they can also be printed large and in Braille without causing problems for sighted people.

This is how disabled people explained the Social Model of Disability on a video made for SCOPE, a UK-based disability organisation.

The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

An impairment is defined as long-term limitation of a person's physical, mental or sensory function.[2]

[1] http://www.mediawise.org.uk/wp-content/uploads/2011/03/150515-Diversity-Calendar.pdf

[2] See https://www.scope.org.uk/about-us/our-brand/social-model-of-disability

According to the World Health Organisation some 15% of the world's population live with a disability of some kind. Yet, awareness about adjustments needed to accommodate their needs have not kept pace with the extent to which food outlets have come to acknowledge the dietary requirements of those who are gluten intolerant, coeliac, vegetarian, or vegan, or whose religion prohibits certain foods.

The Paralympics have demonstrated to the world that many people with physical and intellectual disabilities are fitter and more capable than many people without any disabilities. Their achievements have helped to change attitudes. But the notion of the 'superhuman paralympian' has also generated controversy within disability organisations. Some of them dislike the 'superhuman' label the media has attached to these athletes.

The **language** of everyday discourse remains one of the most powerful ways in which they disabled people are discriminated against.

The words we choose to use about disabled people can help to change attitudes and understanding about issues OR perpetuate prejudice and misunderstandings. The choice is with the people who use them.

NOT
"People with physical disabilities find it difficult to enter public buildings with long flights of stairs."
INSTEAD
"People with mobility impairments find it difficult to manage stairs, they need level access into buildings."

"Agnija Dambeni is a wheelchair user."
rather than
"Unlike most people Agnija Dambeni is confined to a wheelchair/wheel-chair bound."

"Gjorgji Gurbesh who has mental health issues."
rather than
"Mentally-ill Gjorgji Gurbesh..."

If he is receiving treatment it might be acceptable to say *"Gjorgji Gurbesh is a mental health service user."* The service is there for everyone, and many of us will encounter a period in our lives when we might need to make use of mental health services.

Being specific also helps people to understand the nature of different disabilities, for instance: *"Maria Mitreski is a person with Down's syndrome."* She is not *"a mongol"* and certainly not *"a spastic."* *"Jovo Schokolov is dyslexic"* is more accurate than saying he is *"wordblind"* or *"can't spell."*

Old habits die hard, so this may require some effort. But, it is a mark of respect to identify people for WHO they are rather than by stereotypes, especially those linked to a disability. (See also Appendix 1)

You should avoid generalised language that might encourage stereotypes, which are often hurtful and offensive, and separate people instead of encouraging inclusivity. Words like *'crippled', 'handicapped', 'deformed'* or *'defective'* have only negative connotations, while the simple, objective terms do not.

"Rudi Gruevski has learning difficulties" is more acceptable that calling him *"a retard"* or *"thick/stupid."* Instead of *"The disabled…"* or *"An epileptic..."* say *"People with disabilities…"* or *"A person who has epilepsy…"*

If you try not to see people as victims of or sufferers from a disability you are less likely to describe them as such.

"Elena Naumov is stricken with cerebral palsy" gives a very different impression to the simple statement – *"Elena Naumov has cerebral palsy."* Rather than interpret how she may feel, ask how she would much prefer her condition to be described. She is unlikely to wish to be called *"a spastic"* – a term once commonly used to describe someone with cerebral palsy.

Disabled people are not all recipients of medical treatment or chronically ill or sick. This means that not all of them are *'patients'*. A *'patient'* is anyone who is receiving specific treatment from the health care professions for whatever reason.

An impairment may have been caused by a disease (like polio or rubella) but the disability is not a disease, and disabilities are not contagious.

Even if there are risks of infection, you should use language that relates the situation to the concerned individual rather than the risk they pose to others. *"Zoran Todorovic is HIV positive/a person with HIV"* is preferable to *"an AIDS carrier."*

Some people require the particular assistance from others. However, it can be demeaning to refer to these personal assistants simply as *'nurses'* or *'carers'* so check what term both parties might prefer - *'personal assistant', 'companion', mother', 'boyfriend'*, for example.

Some *"blind/visually impaired/partially sighted people"* – not *'the blind'* – have guide dogs. These are working animals, with names, so ask about them and check with the owner before petting them.

There are some misuses of impairment terms that perpetuate negative impressions. These include such commonly accepted dictionary definitions as (for blindness): *"unable or unwilling to perceive or understand;" "not based on reason or evidence;"* or *"lacking reason or purpose"* as in *"he ran blindly off the cliff."*

Such uses in everyday expressions continue to imply fault on the part of people with disabilities. Instead of saying someone is *"blind to the truth,"* or *"deaf to reason"* why not say *"unaware/does not understand the information/does not listen?"*

Homes or toilets which are accessible or adapted for use by everyone should be described as such, not as *"disabled toilets."*

There is a difference between exciting interest and inciting/exciting pity. Disabled people welcome support generated by media that draws attention to the barriers they face because the environment remains very inaccessible and non-disabled society's attitudes can be very 'disableist' to disabled people and their needs.

Avoid emotive terms like *"unfortunate," "pitiful," "plight"* and *"burden."* These are likely to give false impressions and allocate blame. When comparing conditions refer to non-disabled people as *"people without disabilities"* rather than *"most people"* or *"normal people."*

Interviewing people with disabilities

These guidelines should make interviews more comfortable for the interviewer and the interviewee.

General points

When talking with a person with disability, look at and speak directly to the person rather than through an interpreter or a companion who may be along.

Use your usual tone of voice and your usual voice inflection.

Offer assistance in a dignified manner with sensitivity and respect. Be prepared to have the offer declined. If the offer is accepted, listen to instructions.

Remember that a person with one disability does not necessarily have additional disabilities. Just because someone is a wheelchair user doesn't mean they are likely to be deaf too.

Do not hesitate to use everyday expressions. It is fine to say *"see you later"* to a person who is visually impaired or *"let's take a walk"* to a wheelchair user.

Specific situations

If a person has communications difficulties, or uses assistive technology to communicate, allow ample time for a response to your question. If you do not understand what a person is saying, ask them to repeat or explain their answer.

When speaking with someone who has learning difficulties, keep your language simple and make your concepts clear. Remember, however, that simple language is not childish language.

When meeting a person who is visually impaired, identify yourself and others who are with you. It is not necessary to speak loudly. Just because someone is blind doesn't mean they are deaf too.

If your interviewee has a guide dog, remember service dogs are working animals. Ask the owner's permission before you pet them.

If you are selecting a place to interview a wheelchair user, make sure the place is wheelchair accessible (and that there is an accessible toilet).

If you are conversing with someone who is a lip reader and you are not using an interpreter:

- speak clearly and distinctly, but do not exaggerate,
- provide a full view of your mouth,
- talk at your usual rate and volume unless you are asked to slow down or speak up.

Remember

Apart from access needs, people with disabilities are no different from non-disabled interviewees and should be treated with equal respect. Be considerate without being patronising. Focus on the person's abilities, achievements, and individual qualities.

Enjoy your conversation.

08

Appendix

Terminology
A Selection of Useful Websites
The Bristol Declaration

Appendix 1 / Terminology

These definitions are taken from the Disability Handbook produced by the National Union of Journalists (UK & Ireland) in 2012. They are offered as a guide only.

ADHD (Attention Deficit Hyperactivity Disorder) relates to learning and behavioural problems which are not caused by any serious underlying physical or mental disorder. It is frequently characterised by difficulty in sustaining attention, impulsive and disruptive behaviour, and excessive activity. Say 'a person with ADHD'.

Autism is a mental disorder originating in infancy that is characterised by self-centred subjective mental activity, especially when accompanied by withdrawal from reality, inability to socially interact, repetitive behaviour, and language dysfunction. Do not say 'autistic' but 'a person with autism'.

Blind describes a condition in which a person has loss of vision. Visually impaired is the generic term used by some individuals to refer to all degrees of vision loss. Say 'sight impaired' or 'low vision'.

Brain injury describes a condition where there is long-term or temporary disruption in brain function resulting from injury to the brain. Difficulties with cognitive, physical, emotional, and/or social functioning may occur. Do not say 'brain damaged'. Do say 'person with a brain injury'.

Chronic fatigue syndrome also called chronic fatigue and immune dysfunction syndrome. It describes a serious chronic condition in which individuals experience long periods of fatigue accompanied by physical and cognitive symptoms. Never ever use terms such as 'yuppie flu', 'malingering' and 'hypochondritis' as they imply personality disorders. Just say a person has chronic fatigue syndrome.

Congenital disability describes a disability that has existed since birth but is not necessarily hereditary. The terms birth defect and deformity are inappropriate. Say 'a person with a congenital disability'.

Deaf refers to a profound degree of hearing loss. Hearing impaired or hearing loss are generic terms used by some individuals to indicate any degree of hearing loss from mild to profound. These terms include people who are hard of hearing and deaf. Hard of hearing refers to a mild to moderate hearing loss that may or may not be corrected with amplification. Say 'people who are deaf ' or 'have a hearing impairment/loss'.

Developmental disability is any mental and/or physical disability usually starting in childhood or teens and continuing indefinitely. It limits one or more major life activities such as self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency.

This includes individuals with mental retardation, cerebral palsy, autism, epilepsy and other seizure disorders, sensory impairments, congenital disabilities, traumatic injuries, or conditions caused by disease (polio, muscular dystrophy etc). It may also be the result of multiple disabilities. Say 'a person with a developmental disability'.

Disability is a general term used for a functional limitation. It may refer to a physical, sensory or mental condition. Do not refer to disabled people as 'the handicapped', 'handicapped persons' or 'in special need'. Impairment details can be used when citing laws and situations such as access issues.

Disfigurement refers to physical changes caused by such events as burns, trauma, disease, or congenital conditions. Do not use the term 'victim' rather say 'adult with burns', or 'child with burns'.

Down syndrome describes a chromosome disorder that usually causes a delay in physical, intellectual and language development and which usually results in incomplete mental development. 'Mongol', 'Mongoloid' and 'Downs child/ person' are unacceptable. Say 'a person with Down syndrome'.

HIV/AIDS acquired immunodeficiency syndrome is an infectious disease resulting in the loss of the body's immune system to ward off infections. The disease is caused by the human immunodeficiency virus (HIV). A positive test for HIV can occur without symptoms of the illnesses that usually develop up to ten years later, including tuberculosis, recurring pneumonia, cancer, recurrent vaginal yeast infections, intestinal ailments, chronic weakness and fever, and profound weight loss. Don't say 'AIDS victim'. Say 'people living with HIV' , 'people with AIDS' or 'living with AIDS'.

Learning disability describes a permanent condition that affects the way individuals take in, retain and express information. The term is favoured because it emphasises that only certain learning processes are affected. Do not say 'slow learner','retarded' etc but do say 'person with a learning disability'.

Mental disability generally comprises mental disability, psychiatric disability, learning disability or cognitive impairment which are acceptable terms. Always precede these terms with, 'person with ...'

Non-disabled is the appropriate term for people without disabilities. 'Normal', 'healthy' (compared to unwell or disabled people) or even the word 'whole' are inappropriate.

Psychiatric disability, psychotic, schizophrenic and other specific terms should be used only in proper clinical context and should be checked carefully for medical and legal accuracy. Words such as 'crazy', 'maniac', 'lunatic', 'demented', 'schizo' and 'psycho' are highly offensive and should never be applied to people with mental health problems. Acceptable terms are, 'people with psychiatric disabilities, emotional disorders, or mental disorders'.

Seizure describes an involuntary muscular contraction, a brief impairment or loss of consciousness resulting from a neurological condition such as epilepsy or from an acquired brain injury. The term 'convulsion' should be used only for seizures involving contraction of the entire body. Do not use 'has fits'. Rather than 'epileptic', say 'person with epilepsy' or 'a seizure disorder'.

Small/short stature describes people generally under 4'10" tall. Never refer to dwarfs or midgets, which imply a less than full adult status in society. Dwarfism is an 'accepted' medical term, but it should not be used as general terminology. Say 'persons of small (or short) stature'.

Speech disorder is a condition in which a person has limited or difficult speech patterns. Never use 'mute' or 'dumb'. Say 'person who has a speech disorder' or 'a person with a speech impairment'.

Spinal cord injury describes a condition in which there has been permanent damage to the spinal cord. Quadriplegia denotes substantial or significant loss of function in all four extremities. Paraplegia refers to substantial or significant loss of function in the lower part of the body only. Say 'man with paraplegia', 'woman who is paralysed', or 'person with a spinal cord injury'.

Stroke is caused by interruption of blood to the brain. Hemiplegia (paralysis on one side) may result. 'Stoke survivor' or 'person who has had a stroke' is to be preferred to stating someone is a 'stroke victim'.

Substance dependence refers to patterns of substance use that result in significant impairment in at least three life areas (family, employment, health etc). Substance dependence is generally characterised by impaired control over consumption, preoccupation with the substance and denial of impairment in life areas. Substance dependence may include physiological dependence/ tolerance withdrawal.

Although such terms as 'alcoholic' and 'addict' are medically acceptable, they may be derogatory to some individuals. Acceptable terms are, 'people who are substance dependent' or 'people who are alcohol dependent'. An individual who has a history of dependence on alcohol and/or drugs and is no longer using alcohol or drugs may identify themselves as 'recovering' or 'as a person in recovery'.

Appendix 2 / A selection of useful websites

- Ableize: Directory of UK support groups for a wide range of impairment conditions.
  https://www.ableize.com/support-groups/
- www.aktiv.mk
- Assocation “Open the windows”
  http://www.openthewindows.org/
- Association “Solem”
  https://iskraroso.wixsite.com/solem
- DAN: Disabled People’s Direct Action Network on Facebook
  https://www.facebook.com/DirectActionNetwork
  Largely of historical interests as it now brings together veteran campaigners and revisits earlier campaigns.
- Disability Hate Crime Network on Facebook
  https://www.facebook.com/groups/disabilityhatecrimenetwork/
  Monitoring and highlight criminal acts directed against disabled people
- Disability News Service (UK)
  https://www.disabilitynewsservice.com/wow-campaign-is-back-and-pushing-for-a-second-house-of-commons-debate/
- European Association of Service Providers for Persons with Disabilities
  http://www.easpd.eu
- European Disability Forum: ‘Nothing about us without us’ NGO bringing together disability groups across Europe.
  http://www.edf-feph.org
- European Network on Independent Living: Members throughout Europe
  http://enil.eu/about-enil/membership/
- International Network for Hate Studies Academic research site which includes section on disability hate crime.
  http://www.internationalhatestudies.com/category/disability-hate-crime-2/
- Macedonian Institute for Media
  https://mim.org.mk/mk/
- National Association of Blind Persons of Macedonia
  http://www.nssrm.org.mk/

- National Association of Deaf Persons of Macedonia
  http://www.deafmkd.org.mk/
- National Council of Disability Organisations of Macedonia
  http://nsiom.org.mk/
- PORAKA: Macedonia Republic Center for the Support of Persons with Intellectual Disability
  http://poraka.org.mk/?lang=en
- Purple Space: a network for 'disability-confident employees'
  https://www.purplespace.org and see https://www.huffingtonpost.co.uk/entry/purple-tuesday-every-day_uk_5b73cc55e4b0182d49aec050
- Rescare - The Society for Children and Adults with Learning Disabilities and their Families
  http://www.rescare.org.uk
- Roaring Girl Productions: Art and activism
  http://www.roaring-girl.com
- SCOPE: Working for equal opportunities for disabled people
  https://www.scope.org.uk/about-us/
- Sisters of Frida: empowerment network for disabled women
  http://www.sisofrida.org/about/
- We are Purple: Bringing business and disabled people together
  https://wearepurple.org.uk/about-us/

Appendix 3 / The Bristol Declaration

This historical document, produced on Saturday 12 September 1998 at an international conference and technology exhibition organised by PressWise (now MediaWise) for the European Commission Information Society Forum, predates the current era of social media but sets out principles of inclusion which have yet to be fully realised. These principles remain vital if **all** citizens are to participate fully in democratic societies.

Members of the European Commission Information Society Forum, together with participants at InfoCity@Bristol '98, assert that the principles of accessibility, affordability, cultural diversity, empowerment, equality, freedom of expression, open democracy, public service and especially freedom of information, must be at the heart of development and promotion of the Information Society.

The key to active citizenship is ACCESS - regardless of age, ability, gender, sexuality, ethnic origin, social status, income, and religious or political beliefs - to the information each person considers is needed to participate fully in society, and to opportunities to express freely ideas and opinions.

For information and communications technologies (ICT) to play an effective role in reducing the democratic deficit and creating an open, informed and informing society, everyone has to have the opportunity to share in the benefits through:

- access to awareness of the potential of the technology;
- access to appropriate training in its use;
- affordable access to the technology;
- access to the decision-making process about the ways in which the technology is applied;
- access by individuals to personal information held about themselves;
- access to systems of redress if such information is inaccurate or is used improperly.

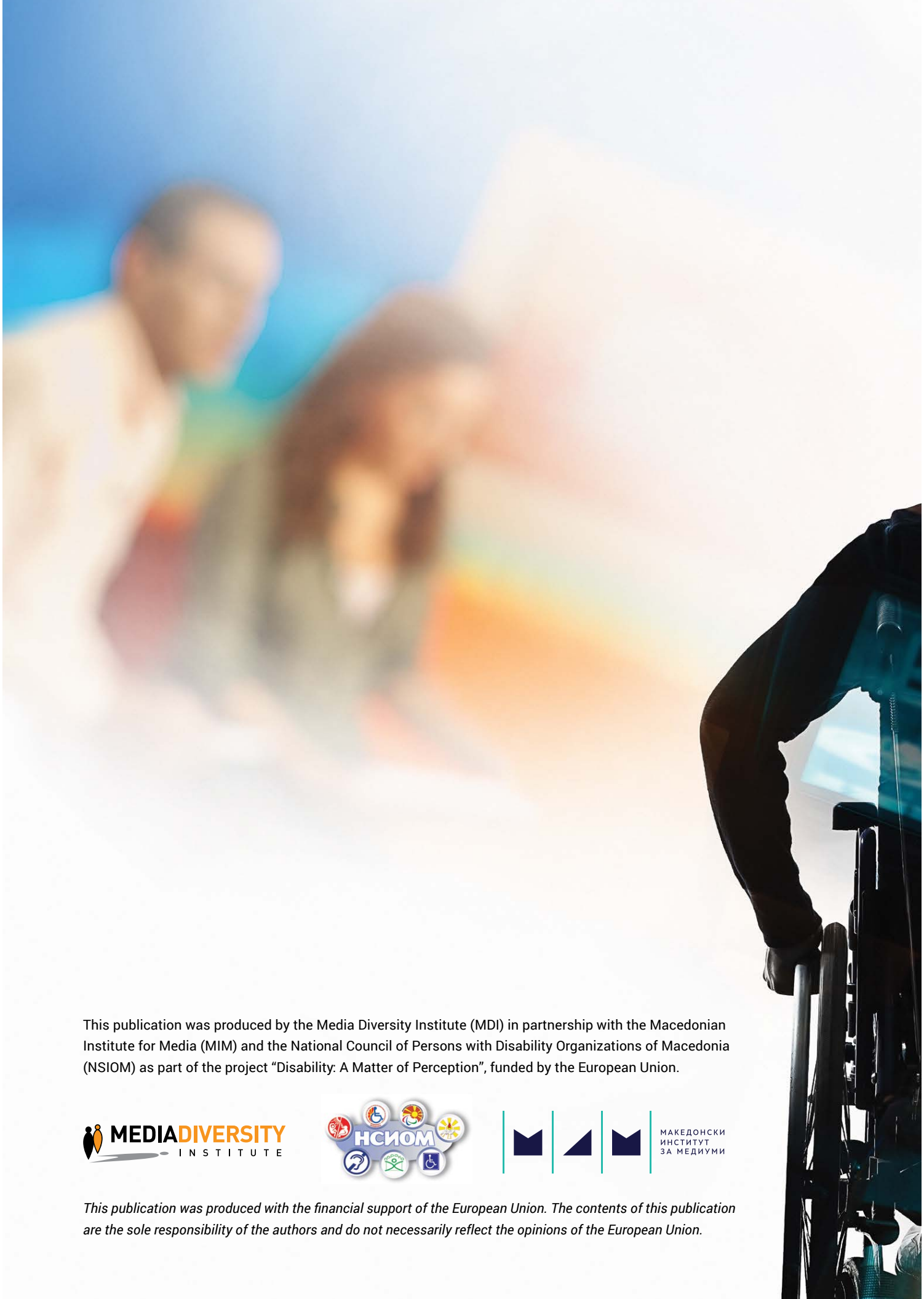
To facilitate democratic participation:

- local and national administrations need to devise and implement coherent strategies, incorporating public consultation, to create a user-friendly infrastructure for the Information Society and, in particular, frameworks for inter-agency co-operation to simplify and improve access to public services;

- educational institutions need to develop accessible systems of service delivery which encourage everyone to make use of opportunities to gain skills and continue education throughout their lives;
- hardware and software manufacturers and information service suppliers must be encouraged to develop comprehensive, harmonised systems that are genuinely accessible by adopting design-for-all policies through the active participation of user groups. Recognising that the market approach cannot of itself guarantee social inclusion, and that many of the most innovative information and communications products come from small companies, the production and distribution of harmonised design guidelines would assist in combating some forms of social exclusion.

With the convergence of ICT it is vital that coherent and harmonised codes of ethical conduct be established, alongside provisions for copyright and data protection and protocols and technical means of assuring the reliability of information reaching the Internet.

These values and aspirations, which echo those outlined in the EC Report People First, The Next Steps (1997), should rank alongside the final principle of the Bonn Ministerial Conference Declaration (July 1997) that 'opportunities for becoming computer literate should be available to people of all ages and from across the social spectrum', and the principle of lifelong learning described in the ISF Newark Declaration (May 1998) that 'education and training is essential for the use of global information networks'.



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