HUMAN RIGHTS: A REALITY FOR ALL

CONFERENCE REPORT

Council of Europe
Disability Strategy 2017-2023

27-28 March 2017
Nicosia, Cyprus

COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

HUMAN RIGHTS: A REALITY FOR ALL

Council of Europe Disability Strategy 2017-2023

27-28 March 2017
Nicosia, Cyprus

CONFERENCE REPORT
Prepared by Dr Sally Witcher,
Chief Executive Officer at Inclusion
Scotland

Council of Europe

Cover and layout: Documents and Publications Production Department (SPDP), Council of Europe

Cover photo : © Soela Zani

Printed at the Council of Europe

Contents

Summary

This is a report on the Council of Europe conference entitled "Human rights: a reality for all", held in Nicosia, Cyprus on 27-28 March 2017, in co-operation with the Cypriot chairmanship of the Committee of Ministers of the Council of Europe. The purpose of the conference was to launch the Council of Europe Strategy on the Rights of Persons with Disabilities 2017-2023 (hereafter the Strategy). It provided a means of fleshing out the Strategy, including giving further details and an analysis of its context, priorities, cross-cutting themes, and approach to implementation.

The Strategy is structured around five rights-based priority areas, five cross-cutting themes, preceded by an outline of the context in which the Strategy is situated, and followed by an approach to implementation. The conference was made up of panel sessions, each focusing on one of the five rights-based priorities, with an additional session on the contribution of the private sector. The opening session included further elaboration of the aims and purpose of the Strategy, while the closing session was devoted to the identification of emerging themes and priorities arising from the presentations and ensuing exchanges, and a look forward towards implementation.

This report therefore broadly echoes that same structure. However, it is important to note that, due to the many complex interconnections between priorities and cross-cutting themes, panel sessions focusing on one of each of the five priority areas frequently touched on other priority areas too. Thus, when reporting on one priority area, sometimes reference is made to points raised in the context of another. Certain cross-cutting themes contained within the Strategy appeared to be particularly associated with certain priority areas. All this was reflected in the interplay of the underpinning human rights. However, it was also the case that, during the course of the conference, additional cross-cutting themes and issues began to emerge. The nature of challenges to implementation took shape, as did recommendations for addressing them. This added significantly to the risks and mitigating actions identified in the Strategy.

A launch-pad for the Strategy was thus forged through the sharing of perspectives, expertise and experience with its foundations deepened by the simultaneous publication of five studies, providing expert exploration of each of the priority areas. The aim of this report is to capture the unique contribution made by the conference towards raising awareness of the Strategy and its wider implications (raising awareness being one of the Strategy's priority areas) and to act as a vehicle through which to facilitate participation, co-operation and co-ordination (one of the Strategy's cross-cutting themes). Examples of good practice, quotes from speakers, and a few extracts from papers are sprinkled throughout the report. Of course, a report like this can only ever provide a flavour of an event involving over 40 speakers! To get a full picture of the Strategy, its starting point and trajectory, it is recommended that this report is read in conjunction with the Strategy itself,[1] the presentations, and the accompanying papers.

Environmental context

As the Strategy makes clear, constantly changing societies generate new situations and new priorities, which impact on persons with disabilities[2] and their support services. In particular, the Strategy highlights the ongoing economic challenges and increasing numbers of refugees and asylum seekers.

It is indeed the case that persons with disabilities have been very hard hit by the economic crisis, and disproportionately so, with disability benefits often being among the first cuts to be made. However, the imposition of so-called austerity measures may be neither a full explanation nor necessarily a full justification for the existence of barriers or failure to remove them, and for the violations of human rights that can ensue. Moreover, as Nils Muižnieks, the Council of Europe Commissioner for Human Rights observed, persons with disabilities face obstacles to the full enjoyment of their human rights even in countries that did not undergo extensive austerity measures, Furthermore:

> The additional support required by persons with disabilities is not optional. It is not a luxury that can be given in economic good times, and taken away when times are hard, when budgets are tight. (Nils Muižnieks, Council of Europe Commissioner for Human Rights)

---

1. Human rights: a reality for all – Council of Europe Disability Strategy 2017-2023, available at: www.coe.int/en/web/disability/strategy-2017-2023.
2. The term "persons with disabilities" is used throughout (with the exception of quotations), in keeping with the language of the United Nations, Convention and the Strategy.

Whereas insufficient resources may be a consequence of lack of political commitment (as suggested in the Strategy),[3] clearly it does not necessarily follow that political commitment alone is enough to guarantee sufficient resources. Dimitrios Karellas, the Secretary General of Welfare of the Greek Ministry of Labour Social Security and Social Solidarity, spoke of the situation in Greece, a country that has been acutely affected by the economic crisis after seven years of recession and austerity measures. He was clear that difficulties in advancing the human rights of persons with disabilities were not attributable to lack of political will but to a lack of resources. But that, despite this, strong emphasis has still been laid on trying to support vulnerable groups, such as elderly people, homeless people, children and young people in need, Roma and persons with disabilities.

The impact of a large-scale influx of migrants and/or refugees was a feature of the contextual landscape highlighted by speakers from Greece and Sweden. Despite the obvious resource implications, there is a pressing need to protect the human rights of refugees with disabilities – a particularly vulnerable group – as explored by Pedro Landfors, Swedish Agency for Participation. This, in turn, can generate significant political, cultural and social challenges.

The rapid pace of technological change (discussed by Daniela Rubio, Advisory Board Member EMEIA for Apple Distinguished Educators, Spain) and the immersion of children and young people in the digital world of social media (explored by Gerison Lansdown, Consultant, United Kingdom) constitute other features of the environment common to all member states. These advances were shown to provide both new opportunities to advance the human rights of persons with disabilities and new threats to these rights.

Thus, there are features of the environmental backdrop to the Strategy that impinge on many, if not all, member states to some degree. Within this context, the UNCRPD[4] serves as "a starting point and a benchmark for implementing any effective disability policy" (Nils Muižnieks, Council of Europe Commissioner of Human Rights). However, while goals and preoccupations may be shared, there is also evidence of differences between member states in terms of the political, economic, social and cultural environment specific to each, and the barriers and priorities arising as a result. Each country is addressing these within their specific legislative framework and institutional infrastructure.

---

3. Council of Europe Disability Strategy 2017-2023, Section 1, paragraph 26.
4. United Nations Convention on the Rights of Persons with Disabilities (2006), available at: www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

They employ different monitoring mechanisms and have established differing methods for involving persons with disabilities. Further complexities and variations "closer to the ground" are also possible where member states have federal or devolved structures. Thus, while many examples of good practice were presented to the conference, and many that could be transferable, perhaps straightforward transferability should not be too readily assumed.

The Strategy offers a common framework through which everyone can work together and learn from each other, while working towards the achievement of shared goals. The rapid pace of change and divergences between member states reinforce the message in the Strategy that "continuous attention to, and action on, the rights of persons with disabilities … is required".[5] This may pose challenges for a strategy that spans six years, in terms of monitoring and evaluation, and in ensuring its ongoing relevance in the face of new barriers and priorities that may emerge during this period.

Council of Europe Disability Action Plan 2006-2015

The new Strategy follows on from the Council of Europe Disability Action Plan that ran from 2006-2015.[6] Alongside the UNCRPD, the action plan marked a paradigm shift away from a medicalised approach to disability towards one based on human rights. The evaluation highlighted achievements in legislation, service delivery, the physical environment and in attitudes. However, it also drew attention to the remaining significant challenges, not least the disparity between standards and practice referred to as the "implementation gap".[7]

Overview of the Strategy

> You might think this new Strategy will not have an impact. You might think it will get lost somewhere. It will get dust on a shelf somewhere. No. It will have an impact. (Luk Zelderloo, Secretary General, European Association for Service Providers for Persons with Disabilities)

---

5. Council of Europe Disability Strategy 2017-2023, Section 1, paragraph 4.
6. Action plan 2006-2015: www.coe.int/en/web/disability/action-plan-2006-2015.
7. Implementation of the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, Abridged Evaluation Report (2015), available at: https://rm.coe.int/168069962d.

Human rights framework

All conventions and charters that have an impact on anyone will invariably have an impact on persons with disabilities. However, sometimes the impact on persons with disabilities will be disproportionate, for better or worse. Sometimes, specific actions will be required to remove barriers and level the playing field for persons with disabilities, if they are to achieve their human rights.

It is thus to be expected that, while the Strategy is anchored in the European Convention on Human Rights (the Convention) and has, as its central focus, the UN Convention on the Rights of Persons with Disabilities (UNCRPD), it is situated within a wider framework of legally binding human rights conventions and charters. That framework encompasses the European Social Charter (particularly Article 15 and Article E), the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention), the Council of Europe Convention on Protection of Children against Sexual Exploitation and Sexual Abuse (Lanzarote Convention), and the Council of Europe Convention on Action against Trafficking in Human Beings.

Those conventions and charters may form the backbone of the Strategy but, in view of the fact that persons with disabilities have multiple characteristics and circumstances (in common with everyone else), it is important to note that all human rights conventions, charters, etc. potentially apply. Indeed, the human rights implications of intersectionality – where persons with disabilities have additional characteristics associated with disadvantage and inequality – are particularly important to consider.[8] For example, other texts referred to during the course of the conference include the UN Convention on the Rights of the Child[9] and the development of an additional protocol to the Oviedo Convention[10] that is currently being pursued by the Council of Europe.

---

[8] For example, see the presentation by Pedro Landfors, Swedish Agency for Participation, concerning the situation for men, women, boys and girls with disabilities in the Swedish asylum seekers and refugees process.

[9] The UN Convention on the Rights of the Child, available at: www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx.

[10] The Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention) sets out fundamental principles applicable to daily medical practice and is regarded as the European treaty on patient's rights. Available at: www.coe.int/en/web/bioethics/oviedo-convention. The proposed additional protocol concerns the review of legal safeguards concerning involuntary placement and treatment of persons with mental disorder.

It is important to note that the Strategy itself does not create or impose legal obligations. However, because it is firmly rooted in a framework of legal obligations it nonetheless carries some legal weight.

Aims, purposes and approach

The **overall goal** of the Council of Europe Disability Strategy 2017-2023 is described as "**to achieve equality, dignity and equal opportunities** for persons with disabilities". This requires ensuring independence, freedom of choice, and full and effective participation in all areas of life and society, including living in the community."[11] Further elaboration of the purposes of the Strategy was provided by Marja Ruotanen, Director of Human Dignity and Equality at the Council of Europe, during the opening session of the conference:

> To support and complement the member States' efforts to build a barrier-free Europe where persons with disabilities can enjoy their fundamental rights … to invigorate ambition with pragmatism: identifying meaningful shared goals to which all Council of Europe member States can and should aspire, and setting out the concrete actions we need to undertake to get us there. (Marja Ruotanen, Director of Human Dignity and Equality, Council of Europe)

This was in the context of the Council of Europe's aim "not just to set standards and uphold the human rights of persons with disabilities, but also to empower persons with disabilities to bring down barriers". Other speakers described it as "a catalyst" and a means of "guiding and supporting" the activities of member states.

The Strategy takes a "twin-track" approach. One concerns "specific projects, campaigns, [training], and activities organised at the national and local levels by national stakeholders in […] member States". The role of the Council of Europe with regard to this track is to "provide support and input such as exchanges of good practices, studies and research". The second track concerns the way in which the Council of Europe itself carries out its business. The aim here is to mainstream disability-related issues throughout all its work and activities. While the role of the Council of Europe is to support member states, there was much discussion during the conference by representatives of member states that could assist the Council of Europe with that process.

---

[11] Council of Europe Disability Strategy 2017-2023, Section 1, paragraph 16.

Structure

The Strategy is structured around five cross-cutting themes and five priority areas. The latter are explicitly underpinned by, and associated with, particular articles in the UNCRPD. Yet, clearly, the cross-cutting themes too are closely linked to articles within that convention,

The five rights-based priority areas are:

1. Equality and non-discrimination (Article 5);
2. Awareness-raising (Article 8);
3. Accessibility (Article 9);
4. Equal recognition before the law (Article 12);
5. Freedom from exploitation, violence and abuse (Article 16).

The five cross-cutting themes are:

1. Participation, co-operation and co-ordination;
2. Universal design and reasonable accommodation;
3. Gender equality perspective;
4. Multiple discrimination;
5. Education and training.

> These principles are often taken for granted and [seen] as self-evident, however, we must remember that often what is taken for granted and as being common, is exactly what is at more risk of being ignored. (Zeta Emilianidou, Minister of Labour, Welfare and Social Insurance, Cyprus)

While each priority area provides a helpful focus around which to structure action and debate, as the conference progressed the sometimes complex interplay between priority areas, between cross-cutting themes, and between priority areas and cross-cutting themes became clearer. This is echoed by the interplay between articles in the UNCRPD, even if each priority area is primarily associated with one article in particular.

The Strategy draws attention to the role the private sector has to play in advancing the human rights of persons with disabilities,[12] and the levers for action provided by international standards on social, including corporate, responsibility. The roles of the UN Global Compact[13] and the UN Sustainable Development Goals (SDGs)[14] are cited in this context as tools for improving the

---

[12] Council of Europe Disability Strategy 2017-2023, Section 1, paragraph 24.

[13] UN Global Compact, available at: www.unglobalcompact.org/.

[14] The UN Sustainable Development Goals, available at: https://sustainabledevelopment.un.org/.

inclusion of persons with disabilities in society. Debate during the conference also drew attention to the UNCRPD articles that are of particular relevance to the activities of private sector businesses. Furthermore, as highlighted by several speakers, a key lever with which to influence the practices of those concerned with making a profit relates to the strong business case for taking action to respect and implement the human rights of persons with disabilities.

The intended beneficiaries of the Strategy are persons with disabilities residing in member states, and society as a whole. This seems to be based on the premise that, through greater inclusivity, enabling persons with disabilities to play an active role and accessing the untapped resources that persons with disabilities have to offer, society is enriched and rendered more cohesive. It may also be helpful to note that, while persons with disabilities are "beneficiaries" of the Strategy, this does not imply passivity. Along with the many stakeholders involved in delivering the Strategy, it is clear that persons with disabilities themselves have a key role to play. This is in line with the cross-cutting theme "Participation, co-operation and co-ordination", and was evidenced by the number of conference speakers and participants who were themselves persons with disabilities, as well as by the recurrent refrain throughout the conference of "nothing about us without us".

Overview of the conference

> Human Rights: a reality for all – the title of this conference – was inspired by our belief that all persons, of all abilities, should have access to and enjoy the full range of human rights. This reflects the shift of focus at the Council of Europe: from disability to ability. (Marja Ruotanen, Director of Human Dignity and Equality, Council of Europe)

The stated aim of the conference was to identify how all actors in the Council of Europe member states and within the Organisation can work together to realise the objectives of the Strategy over the years to come. To that end, it brought together representatives of the governments of the 47 Council of Europe member states, representatives of international organisations, local and regional authorities, professional networks, non-governmental organisations (NGOs), the media and the academic world, and members of parliament in addition to persons with disabilities, specialist bodies and specialised service providers. The conference was organised as part of the Cypriot chairmanship of the Committee of Ministers of the Council of Europe and was hosted by the Cypriot Ministry of Welfare, Labour and Social Insurance.

Setting the scene

> Although we represent countries that differ in many respects, we face many of the same challenges and opportunities. (Signe Maria Christenson, Deputy Head of Department for Disabled Persons, Ministry for Children and Social Affairs, Denmark)

The scene was set by an opening panel session involving senior-level speakers from Albania, Andorra, Cyprus, Greece, Portugal, Serbia and Montenegro. From the short interventions describing the activities undertaken by each to implement the UNCRPD, there was evidence of many shared challenges and preoccupations, in addition to considerable differences in terms of how these had been addressed, and how action had been prioritised.

There was evidence of rapid progress following the ratification of the UNCRPD, for example by Albania and Cyprus. This underlines the usefulness of the UNCRPD as a focus and catalyst for action.

Albania

Just a year after ratification in 2013, Albania passed a law on the inclusion of persons with disabilities. Since then, action has included the establishment of a national council for disability with a role in policy making, an increase in the use of sign language, the tackling of infrastructural barriers and the introduction of an incentive programme to promote the employment of persons with disabilities.

Unsurprisingly, the political institutional infrastructure at national, regional and local levels and where responsibilities for the UNCRPD were located, differed between countries. So too did legislative frameworks for anti-discrimination, inclusion and human rights. This in turn was echoed by differences in monitoring mechanisms and approaches to data collection.

Greece

The monitoring of the implementation of the Greek National Strategy for Social Inclusion takes place at national, regional and local levels. Information is then centralised in a registry, which means we have a very clear picture of what is going on in every part of the country … [even] in the smallest … place[s].

Many presenters referred to national strategies and action plans that had been developed to advance the human rights of persons with disabilities.

Montenegro

The first Montenegrin strategy for the protection of persons with disabilities from discrimination and promotion of their equality covers the period 2017-2021. It sets out a programme of activities to promote the full enjoyment of equal human rights and complete protection against discrimination of persons with disabilities throughout all areas of Montenegrin society.

Countries have taken different approaches to establishing involvement and consultation mechanisms through which to obtain the views of persons with disabilities. These ranged from legal requirements to consult (Cyprus), the establishment of organisations or federations of organisations, the involvement of persons with disabilities or representative organisations in working groups on particular topics or in monitoring exercises (Portugal) or to legal requirements to assess inequality (Andorra).

Cyprus

The "Consultation process between the government and other Services for issues concerning Persons with Disabilities Law of 2006 (L.143 (I) / 2006)" defines the Cyprus Confederation of Organisations of the Disabled as the social partner of the state and provides that each public service or department consults with the confederation on decisions that directly or indirectly affect persons with disabilities.

There were several topics that were repeatedly mentioned in presentations and inclusive education was one such topic. There was evidence of a wide disparity, from children with disabilities being unable to attend school, to countries like Portugal, where 20-25 years ago only around 30% of children with disabilities were integrated into regular schools, whereas today that figure is 97%.

Andorra

A project designed to enable the inclusion of children with disabilities in schools and during school holidays has ensured that children are provided with a monitor or coach to support them in participating in activities. As far as possible, they are included in all activities, including at primary school, secondary school and in higher education. Practically all schools have been made accessible in Andorra.

Many participants also referred to measures to promote the employment of persons with disabilities, including quotas (Cyprus, Greece), supported employment programmes (Portugal) or an incentive programme (Albania), and the development of an employment strategy including consultation with various companies to ensure they had made reasonable accommodation (Andorra).

Some reported on action that has been taken to promote independent living, with support from personal assistants, in order to tackle social isolation (Andorra) and to establish supported living arrangements (Greece).

Portugal

Pilot projects are to be developed over the next three years for a new model of an independent living system based on personal assistance. Every person with disabilities can choose their own personal assistant who can help them to carry out a variety of activities, related not only to domestic activities but also those in the areas of employment or education. Such personal assistance projects are to be based in independent living centres that are community-based and which will always have people with disabilities involved in their co-ordination.

Action to help people to maintain their legal capacity and the provision of supported decision making was referred to by some (Andorra, Cyprus). In Andorra, a working party has been set up to achieve consensus and to change the law. Another recurrent topic was the introduction of financial support to meet the extra costs of disability (Cyprus, Portugal).

Action regarding defining and assessing disability was highlighted by some, including how to move from a form of assessment based on a medical model approach to one based on the social model (Albania, Cyprus, Greece).

There were also examples of quite specific initiatives, such as Greece's action to promote the adoption of children with disabilities, or the introduction by Serbia of a law to facilitate the exercise of rights to movement of blind persons with guide dogs. Representatives of two countries highlighted action to promote the use of sign language (Albania, Serbia).

Serbia

A law has been introduced concerning the rights of deaf people to have access to sign language interpreters when interacting with public authorities, using education, health-care and telecommunication services.

The infrastructural components and most of the key topics that emerged during the opening session were revisited throughout the conference. In effect, they constituted a helpful framework for clarifying what is needed in order to promote the human rights of persons with disabilities and for the discussions to come.

Recommendation

- Common features of a strategic framework for promoting the human rights of persons with disabilities could usefully include: the UNCRPD as a catalyst and focus for action; consideration of the political infrastructure, responsibilities at each level and implications for monitoring and data collection; mechanisms through which to involve persons with disabilities; action on the key topics of inclusive education, employment, independent living, legal capacity and financial support; other specific national priorities; how disability is to be assessed; and how all these are to be synthesised into individual national action plans.

Priority areas

Equality and non-discrimination

Context

The Strategy describes equality as "a core principle of all human rights and fundamental freedoms".[15] The breadth of the theme of equality and non-discrimination (the subject of Article 5 of the UNCRPD), and the extent to which it interconnects with so many other themes makes it a good place to start. Its relationship to other priority areas and cross-cutting themes can be variously construed. Some, such as awareness-raising or universal design and reasonable accommodation, can be seen as strategies to promote equality and non-discrimination. Alternatively, failure to implement other articles can also result in a breach of UNCRPD Article 5. Gender equality (UNCRPD Article 6), and multiple discrimination can be understood to be aspects of equality and non-discrimination, and so on. The theme also covers areas not specifically singled out for attention in the Strategy, although nonetheless important, such as the rights of children with disabilities (UNCRPD Article 7).

Article 5 of the UNCRPD concerns the exercise and enjoyment by persons with disabilities of all human rights without any discrimination, and the guarantee of equality of opportunities for persons with disabilities. Its wide-ranging scope, and multiple interconnections with other articles, was reflected in the gamut of topics and interconnections explored in presentations during the panel session dedicated to this theme, which encompassed:

- Overview – including a presentation of the accompanying expert paper;[16]
- The nature and implications of key underlying models and concepts, including the social model, and understandings of "normal" and "independent living";
- Multiple discrimination;
- Scope, topics and fields with a particular focus on employment, health care and political inclusion.

---

[15] Council of Europe Disability Strategy 2017-2023, Section 3, paragraph 49.

[16] Council of Europe study on *Promoting equality and non-discrimination for persons with disabilities*, Waddington, L. and Broderick, A. (2017).

Overview

Article 5 of the UNCRPD covers the equality of all persons before and under the law, and their entitlement to equal protection and benefits of the law, without discrimination. It requires the prohibition of all discrimination on grounds of disability. However, it is not just a matter of simply prohibiting discrimination, that is, not committing acts that would result in discrimination. To truly equalise opportunities requires the development and adoption of proactive, positive measures to remove the barriers that confront persons with disabilities[17] (in this context, equal treatment merely preserves the unequal status quo). This includes measures such as quotas, additional assistance or awareness-raising campaigns targeted especially at persons with disabilities.

Either explicitly or implicitly, the UNCRPD covers discrimination in a variety of forms:

- denial of reasonable accommodation;
- direct discrimination;
- indirect discrimination;
- harassment;
- instruction to discrimination;
- discrimination by association;
- multiple discrimination;
- discrimination based on perceived or past disability.

There are three types of action identified that can contribute to the removal of discriminatory barriers:

- **Reasonable accommodation**: this is defined as "necessary and appropriate modification and adjustments", which are not unduly burdensome and which would enable an individual person with disabilities to enjoy or exercise "all human rights and fundamental freedoms" on an equal basis with others (UNCRPD Article 2). Failure to provide reasonable accommodation is specifically identified as a form of discrimination (see also UNCRPD Article 5.3).
- **General and anticipatory duties**: unlike reasonable accommodation, these duties are not predicated on the needs of an individual. They usually entail conforming to set standards.

---

[17] UNCRPD, Article 5.4.

- **Universal design**: this concerns the duty to design products, environments, programmes and services to be accessible or usable by all individuals, without the need for adaptation (see UNCRPD Article 2). Clearly, if mainstream provision is made more inclusive and accessible, the need for individualised (and thus potentially stigmatising) reasonable accommodation is reduced.

Rights are meaningless if it is impossible to achieve redress when they are not respected. Mechanisms for providing support and redress vary from state to state.

Malta

Associations, organisations and trade unions are entitled to act on behalf or in support of a victim of discrimination and have legal standing in court for this purpose. The National Commission for Persons with Disability (NCPD) is also empowered by law to assist an alleged victim of disability discrimination, for example by providing legal and financial assistance to enforce an individual's rights under the Equal Opportunities (Persons with Disability) Act, and by helping individuals with disabilities to formulate a complaint.

Bulgaria

The Protection Against Discrimination Commission (PADC), a specialised equality body, promotes and enforces non-discrimination on a variety of grounds, including disability. It assists victims of discrimination, carries out independent research and publishes independent reports. It can make recommendations to public authorities and hear individual complaints of discrimination by victims and third parties. If it finds that discrimination has occurred, it can issue legally binding findings, impose fines, and issue mandatory instructions for remedial or preventative redress. It has the power to initiate proceedings at its own discretion against any alleged perpetrator.

To make rights meaningful, as well as supporting individuals to realise their rights, it is important to ensure that data are collected in order to see what impact measures are having in practice, track overall progress and identify priorities for action.

Italy

The Italian National Observatory of Disability has, as one of its tasks, the collection of statistical data on disability in line with Article 31 of the UNCRPD (in co-operation with the National Institute for Statistics, Istat).

Austria

The University of Vienna conducted an online survey to identify the level of diversity within the student body, focusing on ethnic affiliation, disability and parents' education, and the relevance of such factors for the selection of studies and advancement, as a starting point for increasing the numbers of students with disabilities, among others.

Models and concepts

The social model. The way in which disability is understood has direct implications for law and policy making. The move from understanding disability in terms of functional limitations arising from a person's impairment (the medical model), to a social model, which construes disability as the barriers arising from societal and institutional failures to accommodate people who have impairments, is reflected in Article 1 of the UNCRPD:[18]

> [p]ersons 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.

In contrast, a medical model directs attention towards measures concerned with rehabilitation and welfare. While such measures certainly have a role to play, in line with the social model:

> [o]n the whole, the UNCRPD seeks to target structural discrimination embedded in institutional behaviour, cultural practices, norms, laws and other political and economic structures in society.[19]

The main way in which states can remove such structural barriers is through legal tools, including obligations to take positive measures and make reasonable accommodation. However, that is not to say all good practice requires a legal basis.

Internal barriers. The focus of the social model is on the removal of often tangible external barriers, which are seen as the problem to be addressed. Such external barriers are relatively easy to get rid of: "we have a stage with no ramp and we've managed to find a solution to that" (Dr Stephen Duckworth, Shaw Trust). However, it is important not to overlook the "internal barriers" that persons with disabilities may experience when they believe themselves to be "the problem".

---

[18] United Nations Convention on the Rights of Persons with Disabilities (2006), available at: www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

[19] Council of Europe study on *Promoting equality and non-discrimination for persons with disabilities*, Waddington, L. and Broderick, A. (2017).

The impact of internal barriers can be particularly acute when disability first affects a family or an individual. The "empowerment model" traces a series of stages from initial shock and denial, through frustration and passive acceptance, then on to experiments, decisions and finally integration.

"Normal". In addition to a focus on rights and the need to remove external barriers, definitions of "normal" can play a key part in supporting – or undermining – positive responses to disability. In a world where no one else has ears, those that do have ears become abnormal! Yet, concepts of normality do not have to be narrowly drawn. As Dr Stephen Duckworth put it: "the reality is that it's normal to be different". Each of us is both unique in some respects while sharing features with others. Either all of us are "normal", or none of us are!

"Independence". Similarly, the understanding of "independence" and "dependence" can be a key component in the formation of attitudes towards persons with disabilities, or to becoming one. The reality is that everyone is dependent on others, on collaborative effort. None of the conference participants flew to Cyprus "independently" by flapping their arms! Thus, the true meaning of independence is not "doing it for yourself", but having choice and control over your life, and being dependent on collaborative effort.

Multiple discrimination

Insights into the complexities of external and internal barriers, and attitudes to "normality", need to inform debates on multiple discrimination. Discussed by several speakers in this session, multiple discrimination refers to situations whereby individuals, or groups of individuals, face discrimination on more than one of the prohibited grounds. The preamble to the UNCRPD elaborates further, describing it in the following terms:

> (...) the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

When people have multiple characteristics or circumstances, each associated with discrimination, the result can be intersectional discrimination, and give rise to "a unique discriminatory experience or new forms of discrimination".[20]

---

[20] Council of Europe study on *Promoting equality and non-discrimination for persons with disabilities*, Waddington, L. and Broderick, A. (2017).

Austria

Non-discrimination legislation relating to disability has specific rules for damages in cases of multiple discrimination. Article 9.4 of the Federal Disability Equality Act provides as follows: "[i]n assessing the amount of the immaterial damages, the duration of the discrimination, the gravity of guilt, the relevancy of the adverse effect and multiple discrimination have to be taken into account".

However, as well as considering the implications of multiple characteristics, it is important to reflect on how hierarchies can exist within any one group. Thus the nature and extent of discrimination experienced by members within any one group may vary. For example:

> There is a discrete hierarchy where certain people with disabilities are seen as being more valuable or valued by society than other disabled people. (Dr Stephen Duckworth, Director of Shaw Trust)

There is research that shows that often people who have had a sporting accident or have been injured during war are put on a slightly higher pedestal than might be the case for others with a disability, while people with mental health issues or learning disabilities are among the most marginalised.

Article 6 of the UNCRPD specifically concerns the multiple discrimination experienced by women and girls with disabilities. To monitor this obviously requires disaggregated data. When the focus is on gender distinction as experienced by persons with disabilities who are refugees or asylum seekers, the collection of data is likely to become even more challenging.

Sweden

The backdrop to a study carried out by the Swedish Agency for Participation was the lack of information on disability and the asylum process, a dearth of disaggregated statistics on gender and impairment type, and a change in the law in Sweden in 2016. The latter will create greater uncertainty for asylum seekers in general. It limited family reunification and introduced a main focus on employment and the ability to support oneself economically. Both may have disproportionately adverse implications for persons with disabilities and thus indirectly discriminate against them. This was something the study was to evaluate. Processes developed for people who have just obtained their visa are incompatible with those relating to the education system and to labour market programmes. While this does not present a problem for people in general, it does not adequately cater for those with disabilities. There is a lack of proper methods and measures with which to identify and respond to the support needs of persons with disabilities, with the result that their rights are not respected.

While many migrants experience discrimination, intolerance and violence, this serves to underline the particularly extreme risk of discrimination likely to be experienced by refugees and asylum seekers with disabilities and the importance of effective co-ordination, as set out in the Strategy:[21]

> refugees and asylum seekers … with disabilities are more exposed to all forms of discrimination as well as exploitation, violence and abuse. A comprehensive, strategic approach to the integration and inclusion of migrants with disabilities is needed both at national and local levels.

Scope, topics and fields

Article 2, paragraph 3, of the UNCRPD stipulates that discrimination on the basis of disability, which prevents the full and equal enjoyment of human rights and freedoms, encompasses "the political, economic, social, cultural, civil or any other field". The need to take action to remove discriminatory barriers thus applies to all kinds of activities, programmes and services. The presentations in this session in particular focused on employment, health care and politics.

---

21. Council of Europe Disability Strategy 2017-2023, paragraph 70.

Employment

> To get to work you have to have lots of other things in place; education, further education, transport, independent living services, a whole range of other things are required, but the ultimate goal, I believe, for many is employment. (Dr Stephen Duckworth, Director of Shaw Trust)

Non-discrimination legislation is in some ways just a starting point. There is much that can be done by way of positive action to remove barriers to employment, for example government financial compensation for employers who incur costs when making reasonable accommodation (not that costs are always incurred).

Estonia

The Labour Market Services and Benefits Act provides for targeted support for unemployed persons with disabilities, including the adaptation of working premises and the provision of specialised equipment. The fund compensates the employer for between 50% and 100% of the cost of making the necessary adaptation.

Finland

The Non-Discrimination Act obliges all employers who employ more than 30 people to take steps to foster equality. This "equality duty" also applies to all public authorities and private sector organisations which exercise public power or perform public administrative tasks, and providers of education. It not only requires that discrimination is prohibited, but that active steps are taken to promote equality.

Not all support is necessarily financial in nature, and not all action necessarily originates with government.

Italy

A project entitled Diversity at Work, organised by the Italian equality body UNAR, Sodalitas, Synesis and the Adecco Foundation for equal opportunities, was designed to create an opportunity for businesses to meet people with disabilities and foreign nationals, allowing for contact between employers and those who often experience discrimination. Participants could apply for a job interview. The event was publicised in the media and was an effective recruitment tool.

Germany

The Federal Anti-Discrimination Agency (FADA) and the Commissioner for Matters relating to Disabled Persons designated 2013 as a thematic year for persons with disabilities and chronically ill persons. During the year FADA, in co-operation with other stakeholders, presented good practice awards to companies integrating persons with disabilities and chronically ill persons in an exemplary manner.

United Kingdom

The Business Disability Forum is a not-for-profit member organisation bringing together business people, persons with disabilities and government agents to discuss reforms necessary to achieve workplace equality, so that persons with disabilities can contribute to business success, society and to economic growth. The forum provides support by sharing expertise, giving advice, providing training and facilitating networking opportunities.

Health and health care

The Constitution of the World Health Organization, defines "health" as "a state of complete physical, mental and social well-being and not only the absence of disease and infirmity."[22] The shift from a medicalised approach to disability towards one based on human rights and the social model does not in any way signal that access to health and health-care services is of no importance. Indeed, it is a human right. Article 25 of the UNCRPD states that: "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability". Moreover, to achieve this requires the removal of barriers in the way health-care services are delivered (in accordance with the social model).

Three key areas for action were identified to achieve a reduction in discrimination:

- **Training**: for medical and paramedical personnel, to enhance their knowledge of disability and the capacities of people with disabilities, and on the application of human rights and the equality of rights.
- **Prevention**: the first stage of any effective policy, at all stages of life.
- **Access to health-care services**: too often poor access is a source of direct or indirect discrimination. This may arise due to poorly distributed

---

[22] The Constitution of the World Health Organization, available at: www.who.int/governance/eb/who_constitution_en.pdf.

> health-care services, and services which lack adequate access or reasonable accommodation at the point of reception, in communication methods and the information provided to persons with disabilities and their families.

Central to tackling these problems is the involvement of persons with disabilities themselves, including in the delivery of training.

> There is an urgent need to work with the disabled people themselves and the organisations that represent them. (Alain Faure, European Disability Forum)

Poland

The "Programme for Life" is for persons of all ages with disabilities, including prenatal support for parents. It combines social and medical elements, consisting of psychological support, medical treatment and rehabilitation, in addition to the co-ordination of services.

Political inclusion

The importance of political inclusion, and of taking action to remove discriminatory barriers, is a matter of fundamental human rights. Yet, persons with disabilities can experience political exclusion as voters and as prospective politicians. This not only has obvious implications for them, but also for the nature of democracy:

> Can we say that we live in full and inclusive democracies if an important part of the population is left out of elections and political processes? (Mechthild Rawert, member of the Parliamentary Assembly of the Council of Europe)

To tackle this, accessibility needs to be considered in a holistic sense, covering every part of the electoral process (not least because failure to make one element accessible risks comprising the accessibility of the overall process). It necessitates ensuring that polling stations are accessible, rather than treating persons with disabilities as second class citizens by encouraging them to use remote voting. Communications, registration and complaints processes all need to be accessible.

Albania

Bardhylka Kospiri, the Deputy Minister, Ministry of Social Welfare and Youth, recounted that she became disabled 25 years ago. She is the first person with disabilities to be appointed as a deputy minister in the government and this demonstrates the progress that is being made.

Political parties too often act as gatekeepers to the participation of persons with disabilities, controlling who goes onto lists to stand as candidates and how they are involved in internal party structures and processes. Conversely,

> [p]olitical parties can be the game changers with regard to political participation. (Mechthild Rawert, member of the Parliamentary Assembly of the Council of Europe)

A third issue to address is the de-linking of the right to vote from legal capacity – a link which is commonly made in many member states. Yet, according to the Venice Commission,[23] every person with a disability has the right to vote in line with the jurisprudence of the European Court of Human Rights (the Court) and the UNCRPD.

Supported decision making should always be an option.

Council of Europe

The report and resolution recently adopted by the Parliamentary Assembly of the Council of Europe on "The political rights of persons with disabilities: a democratic issue" will be used as a practical guideline showing where efforts need to be made. A video summary has been prepared in international and French sign language, and work on an easy-to-read version of the resolution is underway, soon to be made available on the website of the Parliamentary Assembly.

The adopted resolution calls on Council of Europe member states to consider linking state funding for political parties to their compliance with accessibility requirements. It also asks member states to consider the establishment of quotas for the participation of persons with disabilities in parliamentary and local elections and to provide candidates having disabilities with additional financial support to cover possible extra costs for the conduct of electoral campaigns.

Recommendations

- While legal requirements are key drivers, much good practice can be achieved that does not require a legal basis.
- Member states should provide support to individuals so they can enforce their rights and make them meaningful.

---

[23] The European Commission for Democracy through Law, (Venice Commission), is the Council of Europe's advisory body on constitutional matters.

- It is important to take into account not just the attitudes of others towards disability but of persons with disabilities themselves. The social model has a key role to play in repositioning "the problem" as external barriers.
- We need to challenge narrow concepts of what is "normal". It is entirely normal to be different. Similarly, we need to understand the true meaning of "independence". Everyone is dependent on the collaborative effort of others. Independence essentially means having choice and control over your life.
- It is important to remain alert to the fact that persons with disabilities (in common with everyone else) have multiple characteristics, with different combinations of disability compounding and creating different experiences of discrimination and manifestations of barriers. This can give rise to hierarchies, including those based on forms of impairment.
- There is much that political parties can do to promote democratic inclusion, for example party manifestos should be produced in Easy Read and other accessible formats, and should be published at the same time.
- Better disaggregated data are needed, including on gender, impairment type and on asylum seekers with disabilities.

Awareness-raising

Context

As with equality and non-discrimination, the theme of awareness-raising touches on just about every sphere of life, and thus cuts across all other themes. In that sense, it is rather a vague topic. Yet, as pointed out in the paper written to accompany this session:

> [e]ven in countries where disability-related legislation exists (such as non-discrimination legislation), the efficacy of such legislation is often hindered by public assumptions and stereotypes of persons with disabilities.[24]

The Strategy underlines the fact that: "[p]ersons with disabilities are still confronted with indifference, unacceptable attitudes and stereotypes based on existing prejudices, fear and distrust in their abilities."[25]

---

[24] Council of Europe study on *Awareness raising on the rights of persons with disabilities*, Katrijn Dekoninck (2017).

[25] Council of Europe Disability Strategy 2017-2023, paragraph 52.

Awareness-raising thus has a crucial role to play in challenging negative, ill-informed attitudes. It is complementary to anti-discrimination legislation and necessary for the realisation of human rights. It is relevant to all priority areas and cross-cutting themes. For example, the Strategy highlights the importance of raising awareness of legal capacity and supported decision-making options. Awareness strategies need to take account of multiple discrimination and the fact that persons with disabilities are not a homogenous group.

Article 8 of the UNCRPD provides for the need for states parties to adopt "immediate, effective and appropriate measures" to raise awareness regarding persons with disabilities, combat stereotypes, prejudices and harmful practices and promote awareness of their capabilities and contributions. It also sets out a number of actions to be taken towards that end, including public awareness campaigns to nurture receptiveness to the rights of persons with disabilities. Specific requirements include awareness-raising action regarding contributions to the workplace, fostering respect throughout the education system, encouraging positive media portrayals and promoting awareness-training programmes.

Presentations in this panel session covered:

- Overview – including a presentation of the accompanying expert paper;
- The role of the media;
- Promoting participation.

Overview

Awareness-raising activities can have multiple objectives and audiences, including persons with disabilities themselves.

Promoting positive attitudes

There are many myths to be debunked, including that disability is only a health issue, that persons with disabilities cannot meet performance standards and that workplace adjustments are costly, that accessibility only benefits persons with disabilities, and so on.[26] Disability is regarded as a "monumental tragedy". Persons with disabilities are, "shameful" or "embarrassing" and "objects of pity". Conversely, those who excel, as students or sportspeople, for example, are cast as "superheroes". Having a family becomes "extraordinary", those who

---

[26] Further explanation is available at: www.who.int/topics/disabilities/en/.

challenge assumptions about the asexuality of persons with disabilities and their partners are considered "heroic" or "special".[27]

The imperative to promote the normality of persons with disabilities, and avoid portraying successful persons with disabilities as superheroes, does not mean that a focus on the abilities and achievements of persons with disabilities should be overlooked. Those abilities can include physical abilities. One potentially positive way of raising awareness of the abilities of people with disabilities concerns investing in support for disabled people to participate in sport. This also underlines the fact that disabled people have rights with regard to all areas of life, including sport as a leisure or competitive activity, and access to sport as an activity that promotes good health and supports rehabilitation.

Ukraine

Margaryta Kropivnytska, Deputy Director of the Department of Analytical and Organisational Support, Ministry of Social Policy of Ukraine, recounted that her country has made long-term investments and developments in the area of disability sports infrastructure, dating back to 1989 when sports and rehabilitation clubs for persons with disabilities started to form. These days, Invasport, a specialised institution working to implement government policy, now constitutes a network of centres and clubs at regional, municipal and district levels, and sports schools for children with disabilities. Overall, about 40 000 people with disabilities are involved in different forms of physical culture, rehabilitation and sport activities in Ukraine and almost 40 sports are developing, including sports for people with different forms of impairment.

In addition to objectives in the area of rehabilitation, one of the state's top priorities is to support disabled athletes and national teams to prepare and participate in Ukrainian and international sporting competitions. This includes state support for the development of the Paralympic and deaflympic movements in Ukraine. There is considerable evidence that this support has been successful.

Links and levels

Structures, policies and legislation are all interlinked. The nature of policies and the way we structure services can underpin and reinforce negativity and a focus on disability rather than ability. Examples are health care that is

---

[27] Council of Europe study on *Awareness raising on the rights of persons with disabilities*, Katrijn Dekoninck (2017).

primarily concerned to "cure" rather than "prevent", and policies that literally segregate persons with disabilities away from mainstream schooling and from living in the community. This negativity tends to be echoed in classical awareness-raising campaigns, focusing on negative consequences, what goes wrong, barriers and obstacles rather the abilities and competencies of persons with disabilities.

If policies and services are structured to reinforce negativity, we, usually persons with disabilities, need to be aware that this is a system that we created and/or help to sustain. It is thus very important for us to question ourselves. However, this is not always easy when you are living in a certain environment and working among people who have the same ideas as you. This makes it hard to assess your work critically. This is one reason why it is so important to involve people with different perspectives. Of course, this includes grass-roots disability organisations but also other stakeholders who may be involved.

The case was made that for awareness-raising strategies to be successful and sustainable they need to make an impact on three levels:

- **Individual**: to influence the way people think and reason, which touches upon their identity and attitudes;
- **Social-organisational**: where people interact with their environment; colleagues, friends, and where organisational culture plays a role;
- **Institutional**: where legislation and policies are created, where democratic institutions fulfil a public role.

Push or pull

There are two ways of approaching the development and communication of awareness-raising strategies. The "push principle" takes a top-down approach, telling people what they must do and threatening negative consequences for failure to comply. Of course, people generally do not like being told what to do. They may change their behaviour temporarily just to abide by the new requirement, but they are not intrinsically motivated to do so, and may not be convinced that it is necessary. The message may need to be continually repeated if change is to be sustained. Conversely, the "pull principle" takes a bottom-up approach, involving people with disabilities and other stakeholders with roles to play from the outset to co-create/co-produce the measures to be taken in order to achieve a shared goal. People will be convinced to act because they themselves have created the strategies, making them much more sustainable and effective.

Thus, involving persons with disabilities and other key stakeholders is not just important because it brings fresh perspectives that enable questioning of established cultures and practices; co-production leads to the development of more successful, sustainable strategies:

> Rather than pointing out to people that they are part of the problem, it's much more interesting to make sure they are part of the solution. (Katrijn Dekoninck, Council of Europe expert)

Denmark

Signe Maria Christensen, Deputy Head of Department for Persons with Disabilities, Danish Ministry for Children and Social Affairs, focused on the interface between legislation and awareness-raising. While the ministry for children and social affairs has overall responsibility for co-ordinating disability policy, all public authorities share responsibility for ensuring that their policies benefit persons with disabilities with regard to all aspects of society. Furthermore, the Danish Government has recently decided to introduce a legal ban on discrimination on grounds of disability. But legal requirements and institutional infrastructure are just a first step. Awareness-raising is an important tool when it comes to transforming rights into reality.

Several initiatives have been launched in Denmark that aim to raise awareness of the abilities of persons with disabilities, rather than focus on their disabilities, and to break down barriers and promote inclusion. In January 2016, a Strategy on Attitudes and Disability was published, based on the vision that interaction between persons with and without disabilities should be natural and equal. This can only be achieved if prejudice and uncertainties are addressed. The strategy was developed by the Danish Disability Council, a government-funded body tasked with monitoring the fulfilment of rights under the UNCRPD, advising government and parliament on disability policy, and making proposals for positive changes. The council consists of representatives of a wide array of stakeholders including NGOs, organisations of persons with disabilities, public authorities and organisations, unions and employers' organisations. They are now working with companies, public authorities and others to implement the strategy, which, while it had multiple target audiences, three in particular are highlighted. The first aims to acquaint primary school children with the theme of disability, and teach children to appreciate tolerance and respect for all, including people with disabilities. The second aim is to help companies become more open to employing people with disabilities to the benefit of both. Finally, it is the ambition of the strategy to help empower people with disabilities themselves.

The role of the media

The Strategy refers to the need to: "[p]romote respect, equality, capabilities and active participation, involvement and inclusion of persons with disabilities in the media, entertainment and cultural life as both active actors and users".[28] Taking the meaning of "actors" in a wide sense, when it comes to the media this includes involvement and employment as presenters, in behind-the-scenes roles and at all levels of seniority within the industry.

United Kingdom

Channel 4, a British public service broadcaster established in 1982 by the UK Government, has a statutory public service remit and aims to highlight the cultural diversity of the UK. It broadcast coverage of the 2012 Paralympics and those in Rio in 2016. Not only did this obviously raise awareness of disabled people's achievements as athletes, in Rio almost two thirds of on-screen presenters were disabled people as were 19% of production staff. The latter was possible due to concerted efforts to progress the careers of persons with disabilities already working in the television industry.

Clearly, to have more diverse people employed behind the scenes in making programmes can only enhance representation on screen. But it is a vicious circle. If minorities don't see themselves on TV, then they may not be attracted to work in the television industry. Even where persons with disabilities are featured in shows, it does not follow that such roles are played by persons with disabilities. A new study found that 95% of characters with disabilities in the top 10 TV shows in America are played by able-bodied actors.[29]

It is not just a question of whether characters with disabilities are featured in soap operas and dramas, but whether disability is the focus of portrayal or merely incidental. Ramy El-Bergamy, Channel 4, On-screen Diversity Executive, spoke of trying to create a "new normal" at Channel 4, where incidental portrayal of disabled people is also prevalent.

---

[28] Council of Europe Disability Strategy 2017-2023, paragraph 54 d).

[29] The Ruderman White Paper on Employment of actors with disabilities in television (2016), available at: www.rudermanfoundation.org/wp-content/uploads/2016/07/TV-White-Paper_final.final_.pdf.

United Kingdom

Last year, disabled actress Amy Conachan joined the cast of Hollyoaks, Channel 4's long running soap opera targeted at a younger audience. The role is not centred around Amy's disability. More programmes need disabled actors in storylines where their disabilities are incidental, as opposed to being portrayed as one-dimensional.

This goes to the heart of promoting positive attitudes towards persons with disabilities: not as superheroes, not as objects of pity, and not as one-dimensional people with one-dimensional interests, but as "normal" people who are full members of society. Other strategies include covering disability (in a non-sensationalist way) in mainstream news and ensuring that persons with disabilities are not only invited as commentators when the topic is disability.

Finally, there is proof that increasing diversity in your workforce can enhance your business:

> [t]he need to reflect your customer base within the workforce breeds empathy and understanding, and far from being a hindrance to a business, this diversity can bring strengths, opinions and points of view otherwise overlooked. (Ramy El-Bergamy, Channel 4, On-screen Diversity Executive)

While there is a strong moral case to be made (why wouldn't your campaign, programme or business represent the rich diversity of your country?), it is important to remember that media companies are businesses and thus a business case needs to be made. This extends to challenges about securing media coverage – including how to generate coverage of the Strategy and this conference.

Promoting participation

> The involvement of persons with disabilities through their representative organisations lies at the heart of the UNCRPD, and is captured in the slogan of the disability movement "Nothing about us, without us". (J. Patrick Clarke, Chief Executive Officer, Down Syndrome International)

It stands to reason that a key way of raising awareness about disability is through the participation of persons with disabilities; in the co-production of policies and strategies, in different roles, in politics and public life and throughout society. Participation applies both to the development (and monitoring)[30]

---

[30] In accordance with UNCRPD Article 33.3: "[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process".

of strategy, policy or product and end outcomes or goals to increase participation. Both development processes and outcomes can increase the social visibility of persons with disabilities and are central to awareness-raising and the breaking down of stereotypes.

The European Disability Forum has developed guidance for policy makers and others on how to carry out accessible dialogue with persons with disabilities and their representative organisations. Four principles have been identified:

1. The right to be consulted, as stipulated in Article 4.3 of the UNCRPD.[31]
2. The need for an open, transparent decision-making process, ensuring the accessibility of all communications, websites, meetings, etc., and allowing sufficient time.
3. The need for a protective and regulatory financial framework for civil society organisations, in recognition of their need for financial support and assistance in the area of capacity building.
4. The institutional recognition of the importance of civil dialogue, including an end to ad hoc consultation, and the creation of a structured dialogue with a clearly defined budget and adequate resources.

Malta

The first National Disability Policy for Malta, launched in December 2014, was designed by the Committee for a Right Society, composed of persons with disabilities, relatives, representatives of people with disability and other experts. Moreover, the Maltese Government promotes daily meetings with persons with disability, non-governmental organisations and others. The parliamentary secretary holds regular meetings with stakeholders (including persons with disabilities) working within the disability sector. The parliamentary secretariat also meets weekly with the National Commission for the Rights of Persons with a Disability (the independent mechanism which audits the government in the implementation of the UNCRPD) and the Aġenzija Sapport (a governmental body providing services to persons with intellectual disability) and other stakeholders.

---

[31] UNCRPD Article 4.3 states: “[i]n the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations”.

In light of this framework, the Maltese Parliament passed the Maltese Sign Language Recognition Act, 2015, having discussed the first draft with the Deaf People Association (Malta) and other experts. As a result, Maltese Sign Language became an official language in the country. The Maltese Parliament also passed legislation making the inclusion of at least one person with disabilities mandatory within governmental boards.

Although Ireland is one of just three Council of Europe member states still to ratify the UNCRPD, there is evidence that the work of Irish disabled people's organisations are promoting lasting positive change.

Ireland

About 30 years ago there was a campaign to pioneer mainstream education for people with intellectual disabilities, specifically children with Down syndrome. As a result, 10 children were placed in 10 local schools and Down Syndrome Ireland and the parents paid for a resource teacher to visit the schools each week. Some years later, the government took over the scheme and now over 80% of children with Down syndrome attend mainstream schools, along with their siblings and peers. This scheme opened the doors for other children with disabilities, enabling them to attend their local school with appropriate support.

Other progress includes the government's launch of a Comprehensive Employment Strategy for People with Disabilities. Government departments have to report to an implementation monitoring committee. There have been significant improvements in health-care treatment, particularly for people with Down syndrome, who previously were denied treatment on the basis that it would not significantly improve their quality of life. Recently there has also been greater recognition of the right to vote and participate in political and public life.

Recommendations

- We should continuously question ourselves. Involving people with different perspectives (including persons with disabilities) is an important way of facilitating challenge and promoting better outcomes.
- Involving key stakeholders (including persons with disabilities) in the development of strategies from the bottom up is likely to be more successful than seeking to impose "solutions" from the top down.

- Employing persons with disabilities (including in ministries) can be an excellent way of raising awareness and promoting positive organisational/institutional change from the inside.
- It is important to consider career progression for employees with disabilities in addition to providing entry-level opportunities.
- To encourage disclosure of disability, people need to have a safe environment where they can talk about it and need to feel that they are part of the solution, not the problem.
- Awards can be a good way of raising awareness and promoting good practice.
- It is particularly important to target awareness-raising and the challenging of negative stereotypes at children of a young age. A booklet by the United Nations International Children's Emergency Fund (UNICEF) called *It's about Ability – An explanation of the Convention on the Rights of Persons with Disabilities*, explains the UNCRPD to children (the booklet is used in Cyprus).
- Awareness-raising activities and the media should be more proactive with regard to ensuring that accessible communication formats are used and made available.
- While it is important to raise awareness of the achievements and abilities of persons with disabilities, portraying the normality of disability and persons with disabilities is perhaps even more so.

Accessibility

Context

According to the UN Committee on the Rights of Persons with Disabilities (UNCRPD Committee), accessibility is "a precondition for the enjoyment of human rights for persons with disabilities". Thus, in common with the previous two priority areas discussed, accessibility is a relevant consideration in all priority areas. It is particularly closely associated with equality and non-discrimination and interconnects with all cross-cutting themes, albeit in different ways. For example, "universal design" and "reasonable accommodation" are methods of enhancing accessibility. To tackle multiple discrimination, it is necessary to explore and address the particular access issues for persons with disabilities who have other characteristics disproportionately associated with inequality.

Accessibility is often thought of only in terms of access to the built environment. However, Article 9 of the UNCRPD extends well beyond this to encompass access to all products and services. It features in Article 4 (General obligations), and Article 3 (General principles) and thus applies to all rights within the convention. It has also been the subject of guidance from the UNCRPD Committee.

Accessibility is necessary if persons with disabilities are to know about their rights, if they are to be enabled to realise them and to seek redress if these rights are violated.

The Council of Europe Disability Strategy, however, has a particular focus on access to information, information technologies and the communication sector.[32] It therefore also interconnects with UNCRPD Article 21, which defines access to information, and UNCRPD Article 2, which provides definitions of communication and language.[33] It is important to note that accessibility applies equally to public and private sectors.

Presentations in this panel session covered:

- Overview – including a presentation of the accompanying paper;[34]
- Children and the digital world;

Overview

It stands to reason that: "without accessibility disabled people are placed at risk of exclusion, at risk of exploitation, at risk of poverty, and at risk of being regarded as different" (Professor Anna Lawson, Council of Europe expert). However, while the benefits to disabled people are obvious, accessibility is an issue for the whole of society, both in terms of costs that accrue due to inaccessibility and the benefits that arise by addressing it:

It is important to recognise the many and varied forms that access issues can take:

> Getting on and off camels is really hard work, especially with a language barrier, and people aren't sure how to help you. With a bit of communication and awareness training, we made it work. (Emily Rose Yates. Accessibility Consultant)

---

[32] Council of Europe Disability Strategy 2017-2023, paragraph 56.

[33] It also has implications for awareness- raising (UNCRPD Article 8), where the target audience is persons with disabilities.

[34] Council of Europe study on *Accessibility of information, technologies and communication for persons with disabilities,* Professor Anna Lawson, (2017).

Nonetheless, access to the built environment is often what first comes to mind when accessibility issues are discussed. The UNCRPD is unequivocal – access considerations apply to all buildings. However, there can be resistance to taking retrospective action to adapt older buildings on grounds of cost, construction challenges or aesthetics. The validity of such grounds is highly debatable:

It is also important to note that, even if such physical access issues are addressed, that alone may not be sufficient to achieve equality of inclusion.

> The most accessible venue in the world is brilliant, but if the staff there don't know how to communicate with me as a disabled person, that's no good. (Emily Rose Yates, Accessibility Consultant)

But once access is in place and attitudes are positive, persons with disabilities can achieve a great deal.

Moreover, if accessibility is to be achieved, the whole of society has a role to play in bringing it about. The breadth of coverage of Article 9 and its implications are illustrated by a couple of complaints brought before the UNCRPD Committee, one concerning a case in Hungary about the inaccessibility of cash machines used in banks (resulting in recommendations on minimum accessibility standards for financial services), and another concerning the lack of accessible information available to blind people on the tram system in a city in Austria.

Finally, the importance of accessibility and how to make it a reality can be summed up as follows:

> Accessibility is about the human, it's about us as human beings, it's about accessibility as a human right. And it's also about accessibility being placed within the central DNA of organisations, because it won't be achieved unless accessibility is that embedded. (Professor Anna Lawson, Council of Europe expert)

The Council of Europe study sets out seven key issues to be taken into account by governments and others when addressing accessibility.

1. **Involve disabled people's organisations**[35] as a fundamental starting point for action throughout the UNCRPD (Article 4.3).

---

[35] There are, of course, communication and other barriers to address to ensure that involvement itself is fully accessible.

France

The Interministerial Observatory on Accessibility and Universal Design (OBIAÇU) was established in 2010, and charged with seeking, recording, evaluating and disseminating examples of good practice in accessibility and universal design. The observatory has a membership of 57, which includes representatives of different territorial authorities, the government, organisations of persons with disabilities, accessibility professionals and experts and economists.

2. **Strategic commitment and ongoing monitoring** highlighting the importance of developing strategies and plans, allocating resources and setting and monitoring targets. Longer-term planning and investment may be needed to make existing provision accessible. New services, products, etc. must be accessible from the outset.

3. **Accessibility standards and guidelines.** Given that it crosses national boundaries, international co-operation is particularly important with regards to information and developments in information and communication technology (ICT).

European Union

Mandate 273[36] called for the elaboration and adoption of European standards in the field of ICT for persons with disabilities and elderly people based on the approaches "design for all" and "assistive technology". In 2014 an accessibility standard was adopted relating to ICT products and services in public procurement processes.

England

The English National Health Service recently introduced its Accessible Information Standard, developed through extensive consultation with patients. It broadly entails recording on a central system the communication preferences and information requirements of disabled patients, including disabled parents of children using the health service, and then making these details accessible to all health-care professionals who come into contact with them.

---

[36] EU M/273, Mandate to CEN/CENELCE/ETSI for Standardisation in the field of information and communications technologies (ICT) for disabled and elderly people, available at: http://ec.europa.eu/growth/tools-databases/mandates/index.cfm?fuseaction=search.detail&id=183.

4. **Embedding accessibility into legislation** by adopting a mainstreaming approach, whereby accessibility standards are incorporated into all forms of legislation (as health and safety requirements have been) to provide a firm legal grounding (via licensing or inspection systems, for example). The European Accessibility Act is a key example.

Norway

In Norwegian law the universal design provision means that failing to provide services and activities for the public in a manner consistent with universal design will amount to discrimination, unless doing so would constitute an undue burden.

5. **Embedding accessibility into the spending of public funds,** including procurement and grants to charities or for research.
6. **Research and data gathering** involves both specific research on accessibility and embedding accessibility into research on ICT.
7. **Training, awareness-raising and knowledge sharing** involves embedding accessibility into formal training for IT specialists, service providers and employers, in addition to raising awareness about and giving guidance on accessibility, including to disabled people.

Estonia

The BE Here. Access for All project for service providers is an example of the steps being taken to improve accessibility for persons with disabilities. The project encourages participating organisations to display signs indicating that their premises, operations and information are accessible to people with disabilities. The scheme also facilitates mutual learning.

The European Accessibility Act[37] has two strands. The first is addressed to economic operators (namely businesses). It imposes accessibility requirements on carefully selected goods and services. The second strand is addressed to public authorities. The aim is to promote consistency and to make sure that what industry is asked to do reflects what public authorities are asking to buy. It covers the procurement of goods and services that already fall under European legislation.

---

[37] Proposal for a Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility requirements for products and services available at: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2015:0615:FIN.

A directive about web accessibility[38] was adopted last year by the European Parliament and the Council. In about a year's time all public sector websites will have to be accessible (with a few exceptions). The directive acknowledges that EU institutions themselves should take the lead in implementing website accessibility.

Children and the digital world

Children these days grow up in a digital world. Increasingly, they do not differentiate between the online digital environment and "offline" physical world, and operate seamlessly between them. They make use of wider ranges of digital platforms and at ever younger ages.

Research with children tells us that they see access to the digital environment as a fundamental right, that it is integral to how they want to conduct their lives. It is also essential to the realisation of the spectrum of human rights, including the right to be included, to be heard, to information and to freedom of expression and association. It also raises issues on the right to protection from sexual exploitation and to privacy. In terms of impact, we know that children make extensive use of social media to build friendship networks. Being unable to access social media thus has obvious implications for social inclusion.

In view of the critical importance of the digital environment to children and to the realisation of their human rights, the absence of any research on the implications for children with disabilities constitutes a huge gap. There are two key barriers:

- Can children with disabilities access the digital environment? If not, what are they missing out on? How can access be opened up to them?
- When in a digital environment, what support do they need to be able to explore it fully, safely and effectively?

Barriers to accessing the online environment could take different forms for people with different impairment groups. It might be a matter of physical access in relation to the right hardware (such as the design of keyboards) or software (for people with visual impairments, for example). There might also be barriers with regard to guidance and support, including the all-important peer support. There could also be intersectional access barriers for children

---

38. Directive about web accessibility, available at: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016L2102.

with disabilities who are from Roma communities or who are refugees or asylum seekers, for example.

Being able to access the online environment might nonetheless bring some particular issues – both good and bad – for children with disabilities. For example, it might open up social networks to children with disabilities who experience barriers or who fear rejection in the offline physical world. But could there be difficulties converting online virtual friendships into friendships in the physical world? Might schools over-rely on online distance learning to avoid making reasonable accommodation to school premises, thereby denying children physical access and interaction with their peers? And could risks of sexual exploitation or cyber-bullying be exacerbated for children with disabilities?

> [T]here's a question…about whether the digital environment operates as a liberation for young people, or whether it operates as a prison, or whether it operates as both. (Gerison Lansdown, Council of Europe consultant)

The digital world is not going to go away. Together with children with disabilities, we need to explore how they can empower and protect themselves, ensuring that they enjoy the benefits of access, but not at the expense of exposing them to harm.

Testimony by Andreas Solomou

I'm a law student. I'm 20 years old. … We're talking today about digital literacy, digital communication, digital participation, digital inclusion, and so on. Should we start talking about human rights in a digital environment? For me, access to digital environments is very important … I can't imagine a day of my life without access to the internet. The internet for me is a […] whole other world where I can let myself go, my imagination and my creativity go wild and that's where I redefine my world every day. I believe that digital environments provide multiple opportunities for learning, socialisation and general development and creativity. I would also say that they have placed relations among people on a different basis, which perhaps reduces under certain circumstances inequalities that are created as a result of disability … I would characterise myself as a digital immigrant. I began to enter the world of smartphone technology and tablet technology when people of my age were already familiar with them and used terms that I couldn't understand. I had to make great efforts on my own in order to get to the same level as them … So the dilemma is that either we should direct our efforts at digital inclusion of a digital immigrant into a world of digital natives or we should ensure that all young people with disabilities are digital natives … I would

> also characterise myself as a digital nomad … while I'm reading a book in the cafeteria I [can] send my finished project, I [can] communicate with my friends, and I [can] vote in a talent show.

Recommendations

- Involving persons with disabilities is crucial to developing accessibility strategies. They will see access issues that those who have never personally experienced them will miss.
- Given that it crosses borders, international co-operation and consistency are particularly important when it comes to information and ICT.
- Consistency with regard to accessibility can be important in the production of goods and services where these cross borders, and can bring competitive advantages.
- Accessibility needs to be mainstreamed into all legislation and be a condition of procurement procedures or grants made from public funds.
- When considering accessibility, it is important to take account of the many forms it can take, the many places persons with disabilities might want to go and the many things they might want to do.
- Research with children with disabilities is needed to find out about the barriers they face in accessing the digital world, the implications for their rights and opportunities, how to remove barriers and empower them to use the digital world fully, equally, safely and effectively.
- The human rights implications of social media and the digital world need to be identified and addressed.

Equal recognition before the law

Context

As with previous sections, this theme has cross-cutting implications. The Strategy makes it clear: "[l]egal capacity is in fact connected to all human rights and their enjoyment … Control over one's life and all its aspects are fundamental requirements for the full enjoyment of all human rights."[39] Yet, denial of legal capacity and the associated substituted (in contrast to supported) decision-making and full guardianship schemes, too often remain the reality,

---

[39] Council of Europe Disability Strategy 2017-2023, paragraphs 61 and 62.

particularly for persons with intellectual or psychosocial disability. Attitudes, models of care and even legal practice too often fail to reflect rights under Article 12 of the UNCRPD. Underpinning this are notions of what constitutes "personhood", and a misplaced (if sometimes quite possibly well-intentioned) emphasis on "protection", which instead serves to disempower. Indeed, issues relating to the separation of "legal capacity" (the universal right of everyone to hold and exercise legal personality) and "mental capacity" (the varying abilities of all people to make certain decisions) are fundamental to Article 12 of the UNCRPD.

Article 12 explicitly reaffirms that "persons with disabilities have the right to recognition everywhere as persons before the law" and that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." It also encompasses obligations to provide access by persons with disabilities to the support they may require to be able to exercise their legal capacity, and the need for safeguards to ensure that a person's preferences are respected, conflicts of interest and undue influence are avoided, and financial and property rights are respected. Article 12 is unequivocal. All persons with disabilities have the right to equal treatment before the law and support of whatever level or type required to exercise this right shall be provided.

Presentations in this session covered:

- Overview (including a presentation of the accompanying expert paper);[40]
- Implications for children with disabilities;
- Implications for service providers and support.

Overview

The concept of personhood

A lot of work has been done in Europe concerning equal opportunities, non-discrimination and breaking down barriers. But the underlying issue is that people have had power taken away from them and that we are engaged in a process of restoring autonomy and self-determination. This has implications, not just when taking big decisions but, importantly, also for the small decisions we take every day that enable us to grow in self-confidence and competence.

---

[40] Council of Europe *A study on the Equal Recognition before the Law*, National University of Ireland (2017).

It also has implications for political action, when we combine our voices into collective decision making.

> What's at stake really is the conception of "the person", the system of our law, which is: each person is autonomous unto themselves; and then the operation system, whereby we've actually taken power away from people, and now have the categorical purpose to restore it. (Professor Gerard Quinn, Council of Europe expert)

This poses fundamental questions about who qualifies as "a person". For the last 300 years or so, our political and legal systems have almost exclusively taken cognitive ability to be the essential criterion for personhood. This has obvious implications for people with intellectual disabilities and places an onus on the state's role to "protect", even though this results in taking away the voice of those people.

It is possible to discern two phases of human rights-based responses to legal incapacity. The first, which began in the 1990s, aimed to ensure "protection", was narrowly tailored and proportionate, reduced the use of legal guardianship, and involved tests of capacity designed to distinguish between those functions where a person has capacity and those where they do not, and recognising that a person may have capacity with regard to some functions but not to others. The aim was to regularise the process and make it more like due process in a criminal system.[41] But it did not challenge the underlying supposition that cognitive ability is the essence of personhood or the resulting restriction of rights. Article 12 of the UNCRPD signals a second, completely different phase and a paradigm shift. It marks a fundamental break from the traditional view that cognitive capacity is the essence of what it means to be a person. Mental capacity no longer equals legal capacity and the need for functional tests is entirely abandoned. Guardianship is replaced by support; in particular, supported decision making.

The legal position

Europe is still in the process of transition from the first to the second phase. The European Court of Human Rights (the Court) has still not made the break. Yet the Court has always been clear that historical prejudices against persons

---

[41] Council of Europe, Committee of Ministers (1999), Recommendation No. R (99) 4 on principles concerning the legal protection of incapable adults, 23 February 1999, can be seen as emblematic of this "functional approach" to legal capacity, available at: www.coe.int/t/dg3/healthbioethic/texts_and_documents/Rec%2899%294E.pdf.

with disabilities can become expressed in legislative stereotyping of legal incapacity. Although there have been challenges from some member states, and the fact is that legal capacity is not explicitly mentioned in the provisions of the European Convention on Human Rights,[42] by construing legal capacity in terms of loss of autonomy and identity, which are inherent to a person's private life, it becomes covered under Article 8 of that Convention (the right to respect for private and family life). The Court has also taken the view that the denial of legal capacity via the imposition of a guardian in turn violates a whole series of fundamental rights, including the right to a free trial and access to a court, the right to vote, to live independently within the community, to family life, to liberty and freedom of movement, and to freedom from inhuman and degrading treatment or punishment.[43]

Despite this, the Court's judgments have fallen short of safeguarding in its entirety the legal capacity of persons with disabilities. Neither have they questioned domestic legislation justifying the initiation of guardianship proceedings and limiting legal capacity. Instead, they have focused only on assessing whether the institution of guardianship is proportionate and the existence of procedural safeguards within the process of instituting guardianship. Thus, where legal "protection" of "incapable" adults is deemed necessary, it must be shown to be proportionate to their individual needs and circumstances. Yet:

> Safeguards can be as elaborate as you want. They're not good enough as long as there is a discriminatory legal institution in place. (Boglárka Benkó**,** Registry of the European Court of Human Rights)

Nonetheless, it remains the case that throughout Europe, almost all new legislation preserves functional testing.

> Substituted decision making, including full guardianship regimes (whereby persons are literally stripped of their personhood in the eyes of the law and the society) are still very much the norm in the countries I have visited. (Nils Muižnieks, Council of Europe Commissioner for Human Rights)

That said, action is underway in various countries to explore the scope for a move away from guardianship and towards supported decision making.

---

[42] The European Convention on Human Rights, available at: www.echr.coe.int/Documents/Convention_ENG.pdf.

[43] Factsheet on Persons with disabilities and the European Convention on Human Rights, available at: www.echr.coe.int/Documents/FS_Disabled_ENG.pdf.

Cyprus

A working group consisting of representatives of public services, the Cyprus Confederation of Organisations of the Disabled and the Cyprus Bar Association has held long discussions on amending or replacing the existing law and providing for the establishment of a supported decision-making system.

The view of the UNCRPD Committee is that as this concerns a civil right, it should be implemented immediately rather than being subject to progressive realisation. It further implies a challenge to the existence of mental health law as a distinct field, and of enforced treatment. This is not to suggest that the concept of protection has gone away. But it now takes a very different form and focus – on protecting the integrity of the process of discovering the person's will and preferences, and ensuring that so-called "support" does not undermine this.

Ultimately, this is a tale of two paradigms, and the transition from one to the other. Perhaps states are not yet ready to drop partial guardianship, even when simultaneously promoting supported decision making, and there is a need to strengthen the evidence base. It is true, however, that the new paradigm of supported decision making is not without its threats. Member states may well require support to progress towards the point where guardianship is no longer needed.

The UNCRPD has been a useful reference point for driving forward the development of the Court's case law towards the second paradigm, including adopting the concept of "reasonable accommodation" (UNCRPD Article 2).

Not only is the bridge between the UNCRPD and the Convention thus being increasingly strengthened, when interpreting the provisions of the Convention, the Court has regard to the rules and principles of international law, and to the standards within the domestic law of member states. The fact that almost all have ratified the UNCRPD is helpful here. So too should be the Council of Europe's Disability Strategy as "an important contribution to the alignment of international standards" (Boglárka Benkó, Registry of the European Court of Human Rights). However, the wording of the Strategy reflects where we are now, not the wholesale and immediate removal of substituted decision making and its replacement by supported decision making required by the UNCRPD. Instead, it allows that this may be done "as far as possible", and that restrictions on legal capacity should be proportionate and individually tailored. While it is necessary to take a pragmatic approach, there is scope to strengthen the commitment to the goal (and the requirement) of the recognition of full legal capacity of persons with disabilities via supported decision making, and to the achievement of rapid progress towards this goal.

Implications for children with disabilities

Even in the most democratic of countries, entrenched social attitudes can result in the failure to recognise children as equal members of society. This is even more so when it concerns children with disabilities.

The United Nations Convention on the Rights of the Child (UNCRC) is the most important and powerful legal tool with which to challenge this view. It makes specific reference to children with physical or mental disabilities.[44]The UNCRC touches on all aspects of life. Importantly, Article 12 includes the right of a child to participate, to form and express views, which must be taken into account in decision making on matters that affect them,[45] including being heard by judicial and administrative proceedings. States parties have a duty to create the conditions and frameworks to promote this.

There is research evidence that young children can form opinions, although they may not be able to express themselves verbally.

> [T]he full implementation of Article 12 requires the recognition and respect of non-verbal forms of communication, including play, body language, facial expressions, drawing and painting, through which even the youngest children are in a position to show understanding, make choices, and [express] preferences. (Leda Koursoumba Commissioner for Children's Rights, Cyprus)

Supported decision making is one of the contemporary instruments we have at our disposal to support children and adults with cognitive or developmental disabilities in the making of decisions that concern them. It enables adults to take decisions, and children to participate in decisions about their own lives. It necessitates supporting children to develop skills, subject of rights, training adults to support them, and a legal framework that ensures decisions are valid.

---

[44] For example, Article 23.1 of the United Nations Convention on the Rights of the Child provides that "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".

[45] Interestingly, it also permits the "weighting" of children's views in view of their age and degree of maturity. How might that relate to legal capacity and the concept of "personhood"?.

Implications for service providers and support

Services are not a luxury. They should be an essential means of removing barriers. However, it is clear from earlier discussion that the way in which support is provided is of fundamental importance in the context of promoting equal treatment and enabling people to live the lives they choose. It is important for the providers of that support to reflect on this, and ensure that they themselves are not creating additional barriers and disempowerment, rather than being enablers of human rights.

> Support services … should make sure that persons with a disability have the steering wheel of their own life in their own hands. That is, I think, the role that the services of today and tomorrow should play. (Luk Zelderloo, Secretary General, European Association for Service Providers for Persons with Disabilities)

However, there are challenges for service providers to confront concerning the gap between the limitations of current legislative frameworks and the wishes of the service user. It is important to work with the guardianship systems that continue to exist in most of our countries, and train guardians to understand the values and ambitions of the UNCRPD and reflect them in their practice. While guardians and service providers can restrict access to justice, they might also facilitate it by initiating court proceedings on behalf of a person with disabilities and supporting him or her through the process. They might report abuse and exploitation. Although they may sometimes act as advocates or lobby for persons with disabilities, they need to be alert to conflicts of interest. Their role is to contribute towards the creation of conditions that enable people to speak for themselves and not to supplant their voices, recognising that "every person has a will and is capable of making choices" (Luk Zelderloo, European Association for Service Providers for Persons with Disabilities).

It is important to be responsive to fluctuating support needs, as life situations or health conditions change, and to be aware that there are different forms and sources of support that may be appropriate. Support might come from families (although one should not be too hasty to assume that they will always be best placed to speak on behalf of children or young people with disabilities), local communities or peers. Supported decision-making services are obviously key.

Supported decision making means persons with disabilities expressing preferences and making decisions for themselves. It is of crucial importance that the relationship between the person with disabilities and the person providing support is founded on trust. Those providing such support may be relatives or friends, or professionals. Many people in institutions have lost contact with their families. Even those living in the community can be socially isolated and have few family connections. And some do not want to be supported by family members due to tensions and disagreements between them. The important thing is that the person with disabilities can choose who is to provide them with support – and who is not.

The role of the support provider generally includes things like helping the person to understand information and to make decisions based on the person's wishes, and then communicating them to other persons, agencies, etc. Supported decision making can extend well beyond judicial processes or a legal context.

Support should always be person-centred and based on an understanding of the person's particular characteristics and interests.

Latvia

ZELDA, a Latvian NGO, is running a pilot project providing support with decisions concerning legal issues, financial issues, daily living skills and care, health care (although only as far as the doctor's door) and the development of social networks. The latter is particularly important for people moving out of institutions and into the community.

Of course, support too can extend beyond supported decision making. The latter does not replace the role of other services such as social services, although such services are not always adequate. Support might be directed towards various personal outcomes, such as whether to leave school and stand on one's own feet, learn new skills, find employment, etc. In the legal context, it might include preparing or reading documents, assistance when legal capacity is reviewed or to be renewed, and support when communicating with the police.

Recommendations

- ▶ Leadership is needed to drive forward the transition to supported decision making, identify and tackle legal barriers to progress, identify risks and mitigating action, including the development of new support mechanisms and the dissemination of good practice.
- ▶ Misplaced, unwarranted "protection" results in unjustifiable disempowerment and this needs to be acknowledged and addressed. It can entail action to shift the culture of service providers from risk-aversion to risk-enablement.

- Both adults with certain forms of disabilities and children (with or without disabilities), can experience misplaced assumptions about their inability to express preferences, the diminishment of their personhood and legal capacity. There may be useful learning to be derived from comparing the approaches taken by each of the two UN conventions and the support and other activities that have evolved around each.
- Providers of support need to ensure that they themselves are not creating additional barriers and disempowerment, rather than enabling human rights.
- The concept of protection needs to take a new form and find a new focus, one which protects the integrity of the process of discovering a person's will and preferences, and ensures that so-called "support" does not undermine this.
- Despite the inadequacy of legal frameworks that continue to enshrine a role for guardianship, and the capacity of guardianship to disempower via substituted decision making, this situation is not inevitable. With the right training and approach, guardians can carry out their roles in ways which empower, and are in accordance with the spirit of the UNCRPD.
- It is important to be aware that everyone is capable of choices, and we all have the right to make poor decisions**!**
- It is important to consider the wider role of supported decision making with regard to different aspects of a person's needs, and how supported decision-making interfaces with other types of service, such as social services.
- Persons with disabilities must have choice over who provides their support.

Freedom from exploitation, violence and abuse

Context

Compared to the general population, persons with disabilities are more likely to be subjected to violence or abuse of various kinds. Among persons with disabilities, particular groups, including children, young or elderly persons, those facing complex barriers, and migrants and refugees, are disproportionately more likely to experience such abuses. Women with disabilities are more likely than non-disabled women to experience gender-based violence or abuse.

The setting in which persons with disabilities are placed is also a factor, with those living in institutions being particularly at risk.

Article 16 of the UNCRPD provides that: "States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects". It further stipulates that they must take appropriate measures to prevent such abuses, including the independent monitoring of all facilities and programmes. They must also provide appropriate recovery services for those who have been victims of any form of exploitation, violence or abuse, and ensure that effective legislation and policies are in place to identify, investigate and prosecute those responsible

This priority area is not cross-cutting in quite the same way others have been, even though it concerns the core business of the Council of Europe, namely the protection of human rights, and even if it all too often directly impacts on the daily lives of persons with disabilities. However, related articles of the UNCRPD including Article 14 on liberty and security of the person, Article 15 on freedom from torture or cruel, inhuman or degrading treatment or punishment, and Article 17 on protecting the integrity of the person, are all relevant, as is UNCRPD Article 4.3 on participation in decision making and Article 12.4 on legal capacity as preventative measure. Moreover, the realisation of all human rights is a key way to prevent exploitation, violence and abuse.

Presentations in this session together spanned:

- Overview (including a presentation of the accompanying expert paper);[46]
- Violence against women with disabilities;
- Abuse of persons with mental disabilities;
- Prevention, detection and action.

Overview

Definitions and expressions

To understand the implications of Article 16 of the UNCRPD it is firstly necessary to define what is meant by exploitation, violence and abuse and, secondly, to explore the particular ways in which these can affect persons with disabilities.

---

[46] Council of Europe study on *Freedom from exploitation, violence and abuse of persons with disabilities*, Marianne Schulze (2017).

There are no standard definitions of exploitation, violence and abuse. They may concern a one-off incident or a pattern of incidents of controlling, coercive or threatening behaviour, violence or acts of aggression. They may be a matter of physical violence, of sexual abuse and exploitation, or of psychological threats and harm. Interventions that violate the integrity of the person, such as neglect, abandonment and deprivation and financial abuse are all encompassed. Hostility, indifference and ignorance alongside lack of accountability also have key roles to play in generating abusive behaviour towards people with disabilities. Yet, abuse is not necessarily an outcome of attempts to harm. Sometimes people may think they are doing good (often in the guise of protection), yet in fact what they are doing is hurtful and damaging.

There are many specific ways in which the exploitation, violence and abuse of persons with disabilities may be expressed. For example, they may take the form of over-medicating or depriving persons with disabilities of medication. There is very widespread use of psychoactive medication, which is not justified in many cases.

In addition to pharmacological restraint, violence and abuse can take the form of physically restraining people via caged beds, or strapping people to furniture, beds or wheelchairs. It may be a matter of threatening or actively depriving them of care, or using duress when seeking consent for procedures. Such abuses include undesired touching, misogyny, sexual violence and criminal acts. Abuse might also be a matter of depriving persons with disabilities of the right to take risks and make mistakes.

Settings

Although they can take place in public places, including on the street, by their very nature exploitation, violence and abuse are more likely to occur behind closed doors. The risks are generally higher in institutions than in other settings. Perpetrators may be other residents as well as staff. People with intellectual disabilities or mental health conditions can be at particularly high risk. In institutions, unequal relationships of dependency can prevail. It can be hard to identify instances of abuse and to hold perpetrators to account. But exploitation, violence and abuse can also occur in community settings; moving people out of institutions into supported living arrangements in the community does not inevitably mean that such incidents will not arise. They can also occur in the family home,[47] where people can feel contained and "managed" by family members and supposed carers.

Community settings, even family homes, can have the features of an institution. There is no size threshold above which the setting qualifies as an institution and below which it does not. Instead, institutions are defined by other factors, such as by a culture that segregates people from the wider society. People are often forced to live there, with people they have not chosen to live with.

There can be poor management and lack of training for staff when it comes to recognising abuse and supporting people who have experienced it, especially when it comes to people seen to have challenging behaviour.

The need for data

The scarcity of data on what in many ways remains a taboo subject makes it hard to gauge the extent of exploitation, violence and abuse perpetrated against persons with disabilities. Institutions and families are not prone to report it and people experiencing it may be unable to communicate their feelings. Yet, what data we do have point to this being a huge issue, and that persons with disabilities are at significantly higher risk of being exposed to such exploitation, violence and abuse than non-disabled people. Conservative estimates suggest that the incidence may be at least five times greater. Not only does it have a direct adverse impact on the daily lives of too many persons with disabilities, the fear of being mocked, of being exposed to hate crime, can itself inhibit independent living and promote social isolation.

It is also very hard to say how many people in Europe live in an institution. Research[48] suggests that at least one million people in the 28 European Union states live in institutions. Most Council of Europe member states simply do not have enough good data. This is despite the requirement in UNCRPD Article 16.3 for the creation of an independent monitoring mechanism to cover all places where persons with disabilities live their lives. As yet there is no guidance on how (or if) that mechanism is to interface with the independent national monitoring mechanism in Article 33, or the national preventative mechanism

---

[47] Indeed, it is possible that the right to privacy can make it harder to spot abuses in a family setting.

[48] DECLOC (2007): www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf; Mapping Exclusion (2012): www.mhe-sme.org/fileadmin/Position_papers/Mapping_Exclusion_-_ind.pdf; Included in Society (2004): www.enil.eu/wp-content/uploads/2012/07/ECCL_Included-in-Society.pdf.

in the UN Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.

Austria and Germany

The organisation NUEVA (a short form for Nutzerinnen und Nutzer evaluieren, meaning "users evaluate") provides a platform that trains persons with disabilities to undertake, as experts in their own right, assessments of the adequacy of institutions and their compliance with principles of autonomy and independent living, largely through qualitative methods. The findings are shared online.

Violence against women with disabilities

The application of the Strategy's cross-cutting theme on gender equality is nowhere more relevant than when it comes to exploitation, violence and abuse. Women experience violence due to the simple fact of their gender. Media reports routinely demonstrate how widespread gender-based violence is, often taking the form of domestic violence. This is supported by statistics showing that in Europe 50 women die every week from domestic violence perpetrated by men. The incidence of violence against women with disabilities is particularly high. They are often at a greater risk of all forms of violence, both within and outside the home. They are two to five times more likely to be victims of violence than non-disabled women, and around a third of women with a disability or health problem have experienced physical or sexual violence by a partner. They are also exposed to particular forms of abuse due to the intersection of their gender with disability, such as being subjected to sterilisation or abortion against their will.

The Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence, known as the Istanbul Convention, covers all women and girls from any background, regardless of age, race, religion, social origin, association with a national minority, migrant status or sexual orientation, etc. It recognises that some groups of women and girls are at greater risk and requires states to take their specific needs into account. It also recognises that women are disproportionately affected by domestic violence. A non-discrimination provision requires member states to apply all the measures that form part of its holistic response to violence against women, without discrimination on any ground, including disability. States are called upon to address the specific needs of vulnerable persons and provide them with specialised assistance.

The Istanbul Convention is based on four pillars, placing obligations on states to establish integrated policies, prevent and protect women from violence and to prosecute those responsible where it occurs. Integrated policies mean developing a holistic response to violence against women. It entails involving and co-ordinating comprehensive action by many stakeholders, agencies and levels of government.

Prevention includes regularly running awareness-raising campaigns and training courses for professionals who are in contact with victims, tackling negative attitudes and gender stereotypes, actively engaging men and boys and promoting mutual respect in cultures where violence against women is condoned. Where prevention has failed, protection and support is needed for victims and witnesses. This includes police intervention, shelters and telephone hotlines, etc. However,

> It should be borne in mind that it's not enough to set up protection structures and support services for victims. It's equally important to make sure that victims are informed of their rights and know where and how to get help. (Iris Luarisi, member of the Council of Europe Group of Experts on Action against Violence against Women and Domestic Violence (GREVIO))

Finally, when it comes to prosecution, one of the great achievements of the Istanbul Convention is that it defines and criminalises various forms of violence against women as well as domestic violence. These include physical, sexual and psychological violence, stalking, forced marriage and forced abortion or sterilisation. There are also provisions relating to judicial proceedings, such as the protection of image and privacy, allowing victims to be accompanied by a counsellor and to testify without being present.[49]

Once again, there are issues concerning the adequacy and collection of data when it comes to violence against women, and women with disabilities in particular.

Abuse of persons with mental disabilities

People do not always think of persons with mental health conditions as persons with disabilities. Instead, when people are asked who persons with disabilities are, they are most likely to mention persons with mobility problems, then persons with visual impairment, wheelchair users, people who are paralysed or

---

[49] The implications of equal treatment when it comes to women with disabilities. may be worth considering here.

have hearing impairments, and perhaps people with intellectual disabilities.[50] Yet people with mental health conditions, in common with other persons with disabilities, experience exclusion and marginalisation. They can, though, be subjected to particular forms of abuse and stigmatisation.

Not only are people with mental health conditions socially and economically excluded, they look set to be politically excluded too.

There are numerous human rights that can come to the fore when people with mental health conditions are concerned, particularly those in a hospital setting. They include rights relating to the prohibition of torture, to a free trial, freedom and liberty, to private and family life, to an effective remedy and prohibition of discrimination.[51]

Poland

Since 2006, a system of ombudspersons for psychiatric patients has been established within psychiatric hospitals. These ombudspersons include lawyers, psychologists and nurses who, importantly, are totally independent of the hospital director. Their role is to ensure patients' rights are upheld, provide information and deal with complaints. They may dispense legal advice, or act as mediators or therapists.

Dr Błażej Kmieciak, Department of Medical Law, Medical University of Łódź

Prevention, detection and action

If exploitation, violence and abuse are to be prevented, it is first necessary to understand their causes.

There are a number of factors that are known to increase the risk of falling victim to exploitation, violence and abuse. Firstly, it concerns who you are. Persons with disabilities are more likely to experience it than non-disabled persons, women with disabilities more likely than men, children and older persons with disabilities more likely than working age adults. Secondly, risk can be increased by certain life experiences, such as poverty, a low level of education, previous experience of abuse, and high support needs. Thirdly, it can relate to setting, with living in an institution increasing risk.

---

[50] The social model may be what underpins the UNCRPD but this is rarely how the public understands disability, attributing it instead to functional limitations and medical conditions.

[51] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Article 7, available at: https://rm.coe.int/168007cf98.

Detection

Poor education means persons with disabilities can be ill-equipped to speak out about their experiences. They may struggle to set boundaries about touching inappropriately, or even to name body parts. The UNCRPD provides for various professional groups to be trained on the meaning of exploitation, violence and abuse. There is a need for a wide range of people to understand the implications, including carers, family members, medical staff, legal staff, court personnel, and, of course, persons with disabilities themselves.

> [W]e actually need to train everybody to detect abuse in people with disability or every single person that could be abused and it's something that's easily done. (Dr Marios Constantinou, Social Exclusion for Persons with Disabilities, Cyprus)

Some indications of abuse are relatively obvious, such as unexplained bruises, unhealed sores or self-harm. Others may be more subtle, like avoidance of certain family members or care professionals, an excessive need to please others, withdrawal and extreme passivity, or an unkempt appearance.

While the way in which disabled people are portrayed in the media can fuel public hostility and hate crime, when it comes to exposing maltreatment within institutions, investigative journalism can have a crucial role to play.

United Kingdom

The BBC broadcast a documentary exposing violence against people in institutions, which led to quite significant policy change. A more recent Channel 4 documentary followed up the implementation of this new policy.

Action

The realisation of the human rights of persons with disabilities is itself a key way to prevent exploitation, violence and abuse. For example, realisation of the right to participate in decision making at all levels (UNCRPD Article 4) and the right of equal legal capacity and support to exercise it as necessary (UNCRPD Article 12). Exploitation, violence and abuse can be symptoms of the denial of a wide range of human rights.

The higher risk of abuse within institutions clearly needs to be addressed. Most obviously, action needs to be taken to move people out of institutions into the community, with individualised support built around their wishes, expectations and choices. That aside, institutions must be open to public scrutiny. Monitoring and inspection are key, but alone are unlikely to solve these issues. Effective procedures for reporting and whistle-blowing also need to be in place, as do systems to prevent and detect violence.

Regardless of where they live, in a more general, broader sense, people need to be empowered to speak up for themselves and professionals need to listen to and act on what they say.

> Frequently, the capacity of persons with disabilities to contribute adequately to discussions is questioned … but the lived experience of persons with disabilities and their informed self-representation must replace the paternalist way of knowing and deciding what is "good for them". It is paramount that the capacity of persons with disabilities is recognised and strengthened and that opportunities are provided to have persons with disabilities speak for themselves on their own terms. (Marianne Schulze, Council of Europe expert)

Persons with disabilities need information about what constitutes exploitation, violence and abuse, and how cases should be reported.

A whole range of actions should therefore be taken to mitigate risks, including strategies to alleviate poverty, promote the choice and control of persons with disabilities over their support and who provides it, provide peer support, access to counselling services, and training and education for all concerned. Support for parents, inclusive education, easy access to assistive devices – all have a role to play. Moreover, the need to support people who have been subjected to exploitation, violence and abuse must not be forgotten. UNCRPD Article 16.4 refers to reconciliation procedures and measures aimed at promoting the recovery and rehabilitation of those people.

Recommendations

- Further work is needed to clarify the relationship(s) between the independent monitoring mechanism referred to in UNCRPD Article 16.3, the independent monitoring mechanism provided for under Article 33 and the national preventative mechanism foreseen in the UN Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.
- Much better data are needed on the incidence of exploitation, violence and abuse experienced by persons with disabilities in all settings.
- In accordance with UNCRPD Article 16.3, effective independent monitoring mechanisms need to be established, which give a voice to persons with disabilities and enable data to be collected and made publicly available.
- Data need to be disaggregated according to gender.

- Attention needs to be paid to establishing support systems for persons with disabilities who have fallen victim to exploitation, violence and abuse.
- Member states who have not already ratified the Istanbul Convention are urged to do so.
- Training and support should be provided to people with mental health conditions so that they are able to act as self-advocates.
- Training is needed on how to spot the signs of abuse.
- The role of poverty as a risk factor in abuse needs to be addressed, along with its wider adverse impact on the realisation of the human rights of persons with disabilities.

Roles and responsibilities

> [T]he governments of member States will drive the implementation of the Strategy ... in close co-operation with persons with disabilities, represented by their organisations, and all other relevant stakeholders. These include National Human Rights Institutions, Equality Bodies, Ombudsman Institutions, service providers and civil society.[52]

Given the breadth of scope of the UNCRPD, and the range and types of action that are required to promote equality and combat discrimination, it is unsurprising that many different stakeholders have roles to play. While the obligation may be on the state itself, the provisions of the UNCRPD and the need to take action will filter down to non-state actors.

It is not just a question of the important roles of the private sector and non-governmental organisations. There can be different levels of responsibility within governmental structures. Complexities can arise in federal states, or those featuring devolved administrations of any kind, where competencies are shared (or, potentially, political differences mitigate against co-operation).

Belgium

Compulsory co-operation agreements are accompanied by guidance issued to the various levels in the state on how to deal with the duty to reasonably accommodate.

---

[52] Council of Europe Disability Strategy 2017-2023 – Human rights: a reality for all, available at: www.coe.int/en/web/disability/strategy-2017-2023.

All this underlines the critical importance of states collaborating with non-state actors and with all who have a role to play in delivering, directly or indirectly, the obligations set out in the UNCRPD, in accordance with the cross-cutting theme: "Participation, co-operation and co-ordination". This also underlines the fact that the activities of these many stakeholders need to be strategically marshalled and directed, and that the participation of persons with disabilities will always be a factor. Member states have a key role to play here, including issuing guidance and information to the key stakeholders involved on how to take forward their direct or indirect obligations under the UNCRPD, as this is "crucial to advance equality and to reduce dependency on legal action to enforce rights".[53]

Aside from the key role of member states, there are a few stakeholders in particular whose roles received particular attention during the conference and in the Disability Strategy itself.

Recommendation

- Member states have a key role to play, including ensuring good communications and co-ordination with federal or devolved structures, and issuing guidance and information to all the key stakeholders involved on how to take forward their direct or indirect obligations under the UNCRPD.

Persons with disabilities

As the Strategy states: "[f]ull and effective participation of persons with disabilities in all areas of life and society as a whole is crucial for the enjoyment of all human rights".[54] Moreover, that goal will only be achieved with the participation of persons with disabilities in the design and delivery of strategies, policies and products designed to achieve progress towards it, and the institutions responsible from all sectors, including the Council of Europe itself. Yet, as Nils Muižnieks, Council of Europe Commissioner for Human Rights, observed: "The rallying cry of "nothing about us without us!", which is the guiding spirit behind the UNCRPD is not yet sufficiently respected by policy makers."

---

[53] Office of the United Nations High Commissioner for Human Rights (December 2010), "Equality and non-discrimination under Article 5 of the Convention on the Rights of Persons with Disabilities", UN Doc. A/HRC/34/26, paragraph 17.

[54] Council of Europe Disability Strategy 2017-2023, Section 2, paragraph 31.

The lived experience of persons with disabilities contributes unique added value towards the identification of priorities, understanding of barriers and the development of effective strategies for their removal. Although some conference sessions did not benefit from the perspective of lived experience, such as the one on equal treatment before the law, and a number of speakers with disabilities were there as experts in their field, for example of law, or communications technologies, there were some who spoke about their personal lived experience.

There were numerous examples of different methods and models for enabling the participation of persons with disabilities in different settings. A number of member states have established and funded disability organisations as a route to reaching and involving persons with disabilities. Different degrees of involvement were also featured, from merely informing, to consulting on already formed proposals and strategies, and to co-production of proposals, strategies, etc.

> Co-creation, co-production design … are not only buzz words. They actually work. (Katrijn Dekoninck, Council of Europe expert)

> Without input [from] people with disabilities, I think many of these progressive laws and policies cannot be effective in practice. (Dr Andrea Broderick, Council of Europe expert)

Yet it was also shown that it is important to understand the attitudes that persons with disabilities may have towards themselves and others.

Recommendation

- There are many ways of involving persons with disabilities and scope to develop more. Co-production is the most thorough and effective way to achieve results.

Families

The Strategy makes several references to the importance of involving families, as well as persons with disabilities themselves, and the need for families to be supported and trained in human rights.[55] It is clear that families can play

---

[55] Council of Europe Disability Strategy 2017-2023, for example, the need for member states to involve persons with disabilities and their families in driving forward its implementation (paragraph 25), the need for family support and education on human rights (paragraphs 44, 47), the need to involve families as well as persons with disabilities themselves in developing training, communication and employment initiatives (paragraph 51 c)).

an important supportive role. They may act as effective advocates, thereby strengthening the voice of persons with disabilities. However, family members can also be perpetrators of exploitation, violence and abuse. Well-meant "protection" can lead to disempowerment and loss of voice of persons with disabilities. The way in which families relate to their family member with disabilities seems to be of pivotal importance in shaping outcomes for the latter.

It should not be assumed, although it often is, that family members will always be the best or most appropriate people to speak for a person with disabilities and be their main source of care.

> [P]eople in many cases don't want to be supported by family members, especially in the case of people with psychosocial disabilities, because there can be tensions in families and disagreements and they would rather prefer to have support from a professional. (Ieva Lemaine-Veldmeijere, Director, Resource Centre for People with Mental Disability ZELDA, Latvia)

This can be particularly keenly felt by young persons with disabilities who, in common with their peers without disabilities, may well want to assert their independence and explore the world for themselves, on their own terms. They do not necessarily want to have to rely on their parents or have their parents speak for them, even if the relationship between them is good.

> [No] 18 year old girl [fancies] taking her mom with her to the Sinai desert! (Emily Rose Yates, Accessibility Consultant, United Kingdom)
>
> Families might not always be the right people to speak on behalf of a person with a disability. I'm sure that my son and daughter never would have wanted me to be their spokesperson when they were growing up. (Luk Zelderloo, Secretary General, European Association for Service Providers for Persons with Disabilities)

Recommendation

- Families play an important supportive role in strengthening the voice of persons with disabilities, but they should not be the only ones to speak on behalf of a person with a disability. It is important to work in partnership with families and focus on the common goal to empower persons with disabilities to stand up for their rights.

The private sector

The Strategy highlights international standards on social responsibility, including corporate social responsibility, the UN Global Compact[56] and the UN

---

[56] United Nations Global Compact, available at: www.unglobalcompact.org/.

Sustainable Development Goals (paragraph 24) as key tools when it comes to engaging the private sector with regard to the implementation of the human rights of persons with disabilities. UNCRPD Article 9 on accessibility (including universal design), Article 5 on equality and non-discrimination and Article 27 on work and employment apply to public and private sectors alike, and are clearly very relevant to the latter.

UN Global Compact

The UN Global Compact is the corporate sustainability initiative of the United Nations. To date, it is the world's largest corporate sustainability initiative, with more than 13 000 signatories of which more than 9 000 are businesses across 165 countries. There are also 85 local networks at local, regional and national levels that support the vision of a UN global compact to "mobilize a global movement of sustainable companies and stakeholders to create the world we want" and its mission: "[b]y committing to sustainability, business can take shared responsibility for achieving a better world".

The UN Global Compact sets out 10 universal principles in 4 different areas, namely human rights, labour, the environment and anti-corruption. These are clearly all rooted in human rights and businesses are encouraged to commit themselves to integrating them into their policies and procedures. Then there is the 2030 Agenda for Sustainable Development and the 17 Sustainable Development Goals (SDGs) aiming to address the most important challenges facing the world. Some touch on issues of particular relevance to persons with disabilities, including action on poverty, and the right to education and to decent work. There have also been workstreams, involving UN partners, on the impact of business on the rights of women, children and indigenous peoples.

The UN Global Compact "Guide for Business on the Rights of Persons with Disabilities"

This forthcoming guide, developed through a process of collaboration and consultation, will look at three different areas in which business can impact on persons with disabilities: in the workplace as employees; in the marketplace, as consumers, clients, business partners, and also suppliers; and as members of the community outside solely commercial interests. It explains how businesses can advance the rights of persons with disabilities in alignment with articles in the UNCRPD, the UN guiding principles on business and human rights, and the 10 Global Compact principles. It identifies how the articles in the UNCRPD are relevant to business activities, and illustrates how businesses can respect and support those rights and shows how this can also contribute towards UN Sustainable Development Goals.

The business case

To motivate private sector companies, in addition to giving them guidance on implementing the human rights of persons with disabilities – and possibly as a prerequisite for its use and application – there is a need to construct a business case for action. This needs not only to dispel unwarranted prejudice, stigma and fears about additional cost, but also to promote the business benefits of employing persons with disabilities and considering their needs as consumers.

> [P]ersons with disabilities represent a huge, often untapped, potential as employers, as consumers, and as business partners … considering the needs of person with disabilities can help create innovative products and services which often provide an advantage to a company when entering new markets. This, in turn, helps the company expand their consumer base and increase their profits and returns. (Elena Bombis, Social Sustainability, Legal & Integrity, UN Global Compact)

Employment

Persons with disabilities, no matter how talented, can experience significant discrimination when it comes to recruitment. To remove the multiple barriers that can arise, a comprehensive strategy is required.

Reed Smith, Global Law Firm

Inspired by the Paralympics of 2012, the company formed a Disability Task Force to look at the business and the position of persons with disabilities in the legal profession. This revealed that very few people with disabilities were employed in the legal profession at all.

"Affinity groups" for different diversity groups were established, each with a champion from senior management. Policies were developed on recruitment and on tailoring jobs to meet the needs of people with different forms of impairment. Human Resources, information technology and even catering became involved. Policies across the business were reviewed and targets and time-frames set. The aim was also to encourage disclosure (which can be a real issue – people are afraid of losing their jobs) and promote discussion about disability.

Once there has been a change of mind-set and action starts being taken, it can be a steep learning curve. When people become aware of disabling barriers, they can find it surprising how many there are.

> I couldn't believe we had a building that's only eight years old in the city of London and the doors weren't wide enough for a wheelchair. This was quite remarkable, to me. (David Boutcher, Partner, Reed Smith LLP)

They can also be surprised by the abilities revealed by persons with disabilities.

Some of the business benefits of adopting equality as part of a business's core values, and enshrining in its culture the promotion and development of employees with disabilities may similarly be unexpected.

Finally, learning can include the importance of not making assumptions about what persons with disabilities need or want.

Switzerland

A Swiss health-care company has created employee resource groups for employees with disabilities that provide them with the opportunities to network, exchange views, create innovative. business-focused solutions and continue professional growth and development.

Technology

Information technology. Advances in communications technology can bring benefits to everyone. However, they promise to be disproportionately beneficial to disabled people, particularly where it concerns the development of inclusive apps and platforms in keeping with the principles of universal design. They stand to make a significant contribution towards inclusive education and job integration, and towards enabling persons with disabilities who experience communication barriers to lead full, inclusive lives. It can be important for profit-making companies, though, that creating inclusive applications does not generate additional costs.

In the context of education, it has wider implications, as non-disabled children learn about diversity and how they can, from a young age, start to be an active part in creating inclusive environments for everyone. All students can interact together on shared common ground, regardless of their characteristics.

Technologies may include different types of interactive keyboards with voiceovers, in turn enabling people with visual impairments to interact not just with the written word but imagery too. A blind person who knows Braille can type with Braille keyboards and this is integrated into voiceover. Such inclusive technology has been built into every iPad. Apple is also developing guidelines on providing a platform in which developers can create accessible content.

Assistive technology. This has become cheaper, more available and more capable of being tailored to meet the needs of individuals. Yet, while everything is in place to roll it out, take up is lagging behind. It remains more a matter of charity than of fundamental human rights. However, public or private partnerships could play a key role in taking forward assistive technology, e-accessibility and e-participation in a number of ways.

1. There is a need to make assistive technology and accessibility become the "new normal". European legislation is in place to make this happen, but it is not enforced. Businesses too often resist. "Reasonable accommodation" all too easily becomes "reasonable exclusion".

2. We have to keep the standard human–computer interface up-to-date, simple and stable (for example in the way most people are familiar with smartphone icons). It is imperative that this interface should also be widely accessible and inclusive.

3. The interface must support adaptability and personalisation (we may have the same icons on our smartphones, but we have different apps, etc.). NGOs and other have a key role to play here.

4. Support the development of individualised products. It is NGOs, the care sector and the like who often know what an individual's needs are.

   > [D]isability is not a certain specialised requirement, it's simply part of the process of producing personalised individual products. (Professor Klaus Miesenberger, Johannes Kepler University (JKU), Linz)

5. Use digitalisation and the "internet of things", maximising the potential and minimising the risks. A revolution is taking place. There is a great deal of new technology in the pipeline that could be useful to most people but fundamentally improve the quality of life for persons with disabilities (a remote-control light switch, for example). Service providers, the therapy sector and others need to demand more from industry.

6. Accessibility and assistive technology need to become an integral part of the education curricula for computer science students, architects, and others.

7. Accessibility and assistive technology must remain a social issue. Without action to challenge prejudice and stigma, their benefits will not be realised.

> [I]t's always about rethinking our own behaviour, rethinking how we deal with other people in our society and then we'll learn how we can use the technology not just for the benefit for people with disabilities but for all of us. (Professor Klaus Miesenberger, Johannes Kepler University (JKU), Linz)

Recommendations

- Businesses can do much to progress the human rights of persons with disabilities and should take action accordingly, through reference to the UN Global Compact and Sustainable Development Goals.
- Private sector businesses need to be made aware of the many and varied business benefits of taking disability seriously, and take a strategic approach to transforming their operations, root and branch.
- To encourage disclosure of disability, people need to have a safe environment where they can talk about it and need to feel that they are part of the solution, not the problem.
- Listen to what persons with disabilities say they want – it may well not be what you assume they want – and ask for their input on improvements.
- NGOs, the care sector and others have key roles to play in pushing for the development and application of assistive technology.

The Council of Europe

The Strategy proposes two key strands of action for the Council of Europe. The first concerns providing support and input to member states, to enable them to roll out the Strategy. The second focuses on the Council of Europe itself as an institution, with particular functions, outputs and activities, and how to ensure the human rights of persons with disabilities are mainstreamed throughout. However, the relationship between the two strands may be more iterative than it initially appears. The same applies to the relationship between learning from the activities of member states and how that in turn informs the practices and outputs of the Council of Europe itself.

As previously remarked, it can be hard for those who are not part of it, who do not personally have lived experience as a person with disabilities, to identify and address any barriers arising from the prevailing institutional culture and standard ways of operating. Once again, this points to the importance of involving persons with disabilities themselves, both as independent external experts and as employees (at all levels and in all roles).

The involvement of persons with disabilities was a major cross-cutting theme of the conference and of the Strategy itself. Contributions, for example, on the importance of political inclusion (Mechthild Rawert, member of the Parliamentary Assembly of the Council of Europe) and the value of a diverse workforce, clearly have implications for institutions of all kinds. As Ramy El-Bergamy (Channel 4, On-screen Diversity Executive) observed, it is important – though intrinsically hard – to challenge unconscious bias and thereby stop hiring "like for like".

Of all the sessions, perhaps the one on equal treatment before the law most clearly emerged as a priority for the development of support to member states and persons with disabilities, and as a key function of the Council of Europe itself. It was evident that the practices of member states in general still fall some way short of the requirements of Article 12 of the UNCRPD, and the replacement of guardianship and substituted decision making by supported decision making. The development of new and different forms of support and changing the culture and practices of support-service providers are an important part of that.

Recommendation

- ► The added value of the Council of Europe is demonstrated by its standards and expertise on human rights. It can support national stakeholders in member states in the process of implementing the Strategy and the UNCRPD by providing them with guidelines and other useful tools on the implementation of standards, peer-to-peer exchange (including on good practice), it can also support data collection, and carry out research and studies. At the same time, the Council of Europe should promote mainstreaming of disability-related issues internally and provide support to other intergovernmental committees, partial agreements and monitoring bodies, including through training on and awareness-raising of disability issues.

Next steps

Any strategy, no matter how positive on paper, is only ever as good as its implementation. The challenges of implementing a coherent strategy across 47 member states are in many ways self-evident. The active involvement of all, not just in terms of taking action but also in collecting data and reporting, will clearly be necessary.

The Council of Europe Disability Strategy describes the process to be adopted: "a biennial work plan with a selection of actions and activities (outputs) to be undertaken by the Council of Europe, in co-operation with the member States, will be prepared".[57] To assess progress with the implementation of the Strategy, the Ad hoc Committee of Experts on the Rights of Persons with Disabilities will prepare biennial reports for the attention of the Committee of Ministers of the Council of Europe.

It goes without saying that the involvement of persons with disabilities will also be of critical importance to the Strategy's success.

Addressing the implementation gap

Despite the widespread commitment to the UNCRPD and support for the Strategy expressed throughout the conference, many challenges to implementation have also been clearly discernible. These can emanate from any and all levels: global, European, member state, federal/devolved administrations, local communities – even at individual level when it comes to overcoming internal barriers. Failure to address such challenges results in what has been termed an "implementation gap".

> Good standards are necessary, but not sufficient … I have witnessed on many occasions a huge implementation gap between the legal standards and the reality on the ground. (Nils Muižnieks, Council of Europe Commissioner for Human Rights)

---

[57] Council of Europe Disability Strategy 2017-2023, Section 1, paragraph 30.

The gap between international standards and practice was also highlighted in the evaluation report on the previous Council of Europe Disability Action Plan 2006-2015 as needing to be addressed as a matter of priority. The translation of high level frameworks and strategies into concrete actions that make a tangible positive impact on people's lives "on the ground" is unlikely ever to be a straightforward matter. If the implementation gap is to be addressed, it is imperative to identify challenges and risks, and develop mitigation strategies. The Strategy provides a few examples of risks and mitigating action. However, during the course of the conference, a number of factors were flagged that could undermine effective implementation:

Lack of resources. While lack of resources does not necessarily mean nothing can be done, and having resources does not necessarily mean barriers will be removed, it would be naive to suggest that resources will not be required to implement the Strategy to full effect.

> We draw up these action plans, but in these action plans we don't talk about budgetary problems. (Alain Faure, European Disability Forum)

Lack of leadership and political will. The obvious political challenges of the profoundly uncertain world we currently inhabit, coupled with the fact that persons with disabilities so often have no voice and can be excluded from democratic processes, can mean that their interests come low down on political agendas. Even where politicians do commit to action, the lack of continuity in the political complexion of governments and the individuals in office can compromise progress.

Complex relationships between national state and federal/devolved structures. The Council of Europe's primary relationship is with its member states. Yet many will have federal structures, devolved administrations and/or lower tiers of government. Responsibility for action may be delegated or shared. Such shared responsibilities between levels of government can further undermine effective communication and action.

The rapid pace of change in an uncertain environment. The pace of change of political realignment, economic uncertainty and technological advancement presents challenges when it comes to keeping any long-term strategy current and relevant.

Failure to meaningfully involve persons with disabilities. Due to the social isolation of so many people with disabilities, the readiness of non-disabled people to speak on their behalf and the reluctance of some people with power to really relinquish it, reaching persons with disabilities can be challenging, and instances of meaningful co-production with them as equal partners insufficiently commonplace.

Lack of data. The importance of adequate disaggregated data with which to monitor progress and identify priorities for action was a recurrent refrain throughout the conference.

The role of the media. The media can be a force for good or ill. It plays a major role in shaping attitudes to disability, and not always positively. Yet investigative journalism can play a key role in exposing otherwise hidden instances of exploitation, violence and abuse happening within institutions. Ultimately, media companies are businesses. Emotive human interest stories sell; the launch of a strategy does not.

Negative attitudes. There may be different views about positive attitudes towards persons with disabilities, whether they entail a focus on their abilities and achievements or on their normality. Yet there can be no doubt of the stigma attached to persons with disabilities, particularly those with intellectual disabilities or mental health conditions, sometimes extending to a rejection of their equality as human beings. The implications are widespread, including the rejection of the status of "person with a disability" by people with disabilities themselves.

Poverty. Although only raised as a risk factor in exploitation, violence and abuse, poverty can have obvious repercussions for participation and the realisation of human rights.

Recommendations

- Where key roles and responsibilities are devolved or shared by lower tiers of government, attention needs to be paid by member states and the Council of Europe (as appropriate) to informing, involving, supporting and inspiring them to play their part in taking the Strategy forward.
- Consider whether it makes sense to standardise the data to be collected by all member states in order to monitor progress and identify priorities, and consider what role the Council of Europe might play in this.
- In view of the importance of involving persons with disabilities, consideration needs to be given by member states to the collection of qualitative as well as quantitative data, perhaps by establishing monitoring structures led by people with disabilities, segmented by theme or policy area and capturing local variations.

- The risk register for implementation of the Strategy might usefully be expanded to encompass the challenges identified during the conference, and mitigating actions considered.

Conclusions

Discussion at the conference clearly revealed how priority areas as well as the five identified cross-cutting themes interface with each other, and the role each can play in reinforcing and extending the other. There is no doubt considerably more to be said on multiple discrimination and gender equality in particular than was explored on this occasion. Yet there was much discussed on participation and training, the latter in multiple contexts and for multiple parties and purposes.

> Central to progress is the mantra "nothing about us without us". To invite persons with disabilities along to discussions about them and decisions made that affect them is not just the polite thing to do. Working with persons with disabilities as equal partners will lead to better-informed discussions and better decisions. (Dr Sally Witcher, Chief Executive Officer at Inclusion Scotland, General Rapporteur)

Emerging themes

Throughout the course of the two days, a number of additional cross-cutting themes began to take shape. There was a recurrent focus on children, including the importance of inclusive education, with regard to the digital world of social media they increasingly inhabit and their human rights in that context and more generally:

> Attitudes are founded early in life. So if we want to live in a society based on tolerance and mutual respect, we have to teach our children these values. (Signe Maria Christensen, Deputy Head of Department for Persons with Disabilities, Ministry for Children and Social Affairs, Denmark)

Article 27 of the UNCRPD concerns the duty to ensure non-discrimination in employment. There were numerous examples of different approaches and good practice, in both different countries and sectors. There was much said concerning concepts of "personhood", "human" and "normal", and implications for legal capacity, democratic inclusion, the denial of voice and institutionalisation. For some, people with disabilities were counterpoised against "healthy" people, although disabled people are not necessarily sick or unwell. There was reference to "the new normal":

> The best way to raise awareness is not by launching initiatives and awareness-raising campaigns and posters, but by having a person with a disability as a colleague, as a neighbour, as someone who is studying together with you. (Katrijn Dekoninck, Council of Europe expert)

Finally, the inadequacy of data, their importance if we are really to understand what if happening or not happening and to whom, and the challenges of collecting data, featured throughout the conference.

Looking ahead

While not being naive or unrealistic, or inadvertently, through over-optimism, denying the existence of the real barriers that persons with disabilities continue to confront, there is evidence of progress along the road towards the full realisation of the human rights of persons with disabilities. That said, we know many challenges lie ahead and there is much to be done before "diversity is written into our blood" (Ramy El-Bergamy, Channel 4, On-screen Diversity Executive) and "accessibility is part of our DNA" (Professor Anna Lawson, Council of Europe expert).

> Inevitably, the road leading to the realisation of human rights for all is a long one and often becomes tortuous. (Zeta Emilianidou, Minister of Labour, Welfare and Social Insurance, Cyprus)

The conference provided many examples of good practice and many helpful signposts towards that destination. There was clear evidence that barriers can be removed, a difference can be made. Mind-sets are changing, but are they changing fast enough? Can they keep up? For these are turbulent times. We can expect to encounter new threats along the way. Yet this is also an exciting time of new opportunities, of technological advancement that could do much to promote the inclusion of persons with disabilities:

> We are at the threshold, the dawn of a new era … We have the technologies, we have the legislation, we just need to be willing and work together … to make it happen and to make everyone [fulfil] their dreams. (Daniela Rubio, Advisory Board Member EMEIA for Apple Distinguished Educators)

Ultimately, this is a positive message. It may be a long journey that we have embarked upon but we are not alone. We have each other for company. The conference has shown that there is much we can learn from each other and much we can do to motivate each other to keep going.

> Alone we can do so little; together we can do so much. (Helen Keller, an American author, political activist, and lecturer)

The Council of Europe Disability Strategy provides an invaluable mechanism through which to do just that.

Summary of recommendations

Equality and non-discrimination

- While legal requirements are key drivers, much good practice can be achieved that does not require a legal basis.
- Member states should provide support to individuals so they can enforce their rights and make them meaningful.
- It is important to take into account not just the attitudes of others towards disability but of persons with disabilities themselves. The social model has a key role to play in repositioning "the problem" as external barriers.
- We need to challenge narrow concepts of what is "normal". It is entirely normal to be different. Similarly, we need to understand the true meaning of "independence". Everyone is dependent on the collaborative effort of others. Independence essentially means having choice and control over your life.
- It is important to remain alert to the fact that persons with disabilities (in common with everyone else) have multiple characteristics, with different combinations of disability compounding and creating different experiences of discrimination and manifestations of barriers. This can give rise to hierarchies, including those based on forms of impairment.
- There is much that political parties can do to promote democratic inclusion, for example party manifestos should be produced in Easy Read and other accessible formats, and should be published at the same time.
- Better disaggregated data are needed, including on gender, impairment type and on asylum seekers with disabilities.

Awareness-raising

- Employing persons with disabilities (including in ministries) can be an excellent way of raising awareness and promoting positive organisational/institutional change from the inside.
- It is important to consider career progression for employees with disabilities in addition to providing entry-level opportunities.
- Awards can be a good way of raising awareness and promoting good practice. An initiative in Ireland gave employing persons with disabilities a certain celebrity status.
- It is particularly important to target awareness-raising and the challenging of negative stereotypes at children of a young age. A booklet by the United Nations International Children's Emergency Fund (UNICEF) called *It's about Ability – An explanation of the Convention on the Rights of Persons with* Disabilities, explains the UNCRPD to children (the booklet is used in Cyprus).
- Awareness-raising activities and the media should be more proactive with regard to ensuring that accessible communication formats are used and made available.
- While it is important to raise awareness of the achievements and abilities of persons with disabilities, portraying the normality of disability and disabled people is perhaps even more so.

Accessibility

- Involving persons with disabilities is crucial to developing accessibility strategies. They will see access issues that those who have never personally experienced them will miss.
- Given that it crosses borders, international co-operation and consistency are particularly important when it comes to information and ICT.
- Consistency with regard to accessibility can be important in the production of goods and services where these cross borders, and can bring competitive advantages.
- Accessibility needs to be mainstreamed into all legislation and be a condition of procurement procedures or grants made from public funds.

- When considering accessibility, it is important to take account of the many forms it can take, the many places persons with disabilities might want to go and the many things they might want to do.
- Research with children with disabilities is needed to find out about the barriers they face in accessing the digital world, the implications for their rights and opportunities, how to remove barriers and empower children to use the digital world fully, equally, safely and effectively.
- The human rights implications of social media and the digital world need to be identified and addressed.

Equal recognition before the law

- Leadership is needed to drive forward the transition to supported decision making, identify and tackle legal barriers to progress, identify risks and mitigating action, including the development of new support mechanisms and the dissemination of good practice.
- Misplaced, unwarranted "protection" results in unjustifiable disempowerment and this needs to be acknowledged and addressed. It can entail action to shift the culture of service providers from risk-aversion to risk-enablement.
- Both adults with certain forms of disabilities and children (with or without disabilities), can experience misplaced assumptions about their inability to express preferences, the diminishment of their personhood and legal capacity. There may be useful learning to be derived from comparing the approaches taken by each of the two UN conventions and the support and other activities that have evolved around each.
- Providers of support need to ensure that they themselves are not creating additional barriers and disempowerment, rather than enabling human rights.
- The concept of protection needs to take a new form and find a new focus, on protecting the integrity of the process of discovering the person's will and preferences, and ensuring that so-called "support" does not undermine this.
- Despite the inadequacy of legal frameworks that continue to enshrine a role for guardianship, and the capacity of guardianship to disempower via substituted decision making, this is not inevitable. With the right

training and approach, guardians can carry out their roles in ways which empower and which are in accordance with the spirit of the UNCRPD.

- It is important to be aware that everyone is capable of choices, and we all have the right to make poor decisions!
- It is important to consider the wider role of supported decision making with regard to different aspects of a person's needs, and how supported decision making interfaces with other types of service, such as social services.
- Persons with disabilities must have choice over who provides their support.

Freedom from exploitation, violence and abuse

- Further work is needed to clarify the relationship(s) between the independent monitoring mechanism referred to in UNCRPD Article 16.3, the independent monitoring mechanism provided for under Article 33 and the national preventative mechanism foreseen in the UN Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.
- Much better data are needed on the incidence of exploitation, violence and abuse experienced by persons with disabilities in all settings.
- In accordance with Article 16.3, effective independent monitoring mechanisms need to be established, which give a voice to persons with disabilities and enable data to be collected and made publicly available.
- Data need to be disaggregated according to gender.
- Attention needs to be paid to establishing support systems for persons with disabilities who have fallen victim to exploitation, violence and abuse.
- Member states who have not already ratified the Istanbul Convention are urged to do so.
- Training and support should be provided to people with mental health conditions to enable them to act as self-advocates.
- Training is needed on how to spot the signs of abuse.
- The role of poverty as a risk factor in abuse needs to be addressed, along with its wider adverse impact on the realisation of the human rights of persons with disabilities.

Stakeholders

- Member states have a key role to play, including ensuring good communications and co-ordination with federal or devolved structures, and issuing guidance and information to all the key stakeholders involved on how to take forward their direct or indirect obligations under the UNCRPD.
- There are many ways of involving persons with disabilities and scope to develop more. Co-production is the most thorough and effective way to achieve results.
- Families play an important supportive role to strengthen the voice of persons with disabilities, but they should not be the only ones to speak on behalf of a person with a disability. It is important to work in partnership with families and focus on the common goal to empower persons with disabilities to stand up for their rights.
- Businesses can do much to progress the human rights of persons with disabilities and should take action accordingly, through reference to the UN Global Compact and Sustainable Development Goals.
- Private sector businesses need to be made aware of the many and varied business benefits of taking disability seriously, and take a strategic approach to transforming their operations, root and branch.
- To encourage disclosure of disability, people need to have a safe environment where they can talk about it and need to feel that they are part of the solution, not the problem.
- Listen to what persons with disabilities say they want – it may well not be what you assume they want – and ask for their input on improvements.
- NGOs, the care sector and others have key roles to play in pushing for the development and application of assistive technology.
- The standards and expertise on human rights are the added value of the Council of Europe. It can support national stakeholders in member states in the process of implementing the Strategy and the UNCRPD by providing them with guidelines and other useful tools on the implementation of standards, peer-to-peer exchange (including on good practice), it can also support data collection, and carry out research and studies. At the same time, the Council of Europe should promote mainstreaming of disability-related issues internally and provide support to other intergovernmental committees, partial agreements and monitoring bodies including through training on and awareness-raising of disability issues.

Implementation

- Where key roles and responsibilities are devolved or shared by lower tiers of government, attention needs to be paid by member states and the Council of Europe (as appropriate) to informing, involving, supporting and inspiring them to play their part in taking the Strategy forward.
- Consider whether it makes sense to standardise the data to be collected by all member states to monitor progress and identify priorities, and consider what role the Council of Europe might play in this.
- In view of the importance of involving persons with disabilities, consideration needs to be given by member states to the collection of qualitative as well as quantitative data, perhaps by establishing monitoring structures led by disabled people, segmented by theme or policy area and capturing local variations.

The Council of Europe Strategy "Human Rights: A Reality for All" aims to support and complement the member States' efforts to build a barrier-free Europe where persons with disabilities can enjoy their fundamental rights.

www.coe.int/disability

Prems 124217

ENG

www.coe.int

COUNCIL OF EUROPE

CONSEIL DE L'EUROPE