Towards a Rights-based Approach to Strengthening Leadership and Governance in Health Services

This paper is based on a Background Paper for the WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030. The Background Paper was produced by the WHO/Ireland Working Group on Rights-based Leadership and Governance (see appendix 1) which built on workshops with the European Association of Service Providers for Persons with Disability (EASPD) and the European Disability Forum (EDF). This 2024 version is slightly updated but substantially the same, and is published as an open access document by the *ALL Institute, Maynooth University.*

Suggested citation for this version is:

MacLachlan, M., Morgan, C., Bracken, P., Campbell, A., Colfer, F., Geiser, P., Gleeson, C., Khasnabis, C., Mannan, H., Mishra, S., Naughton, C., Tamming, R.E., Shakespeare, T., Walsh, M. (2024) *Towards a Rights-based Approach to Strengthening Leadership and Governance in Health Services*. Maynooth University: ALL Institute.

Affiliations are provided In Appendix 1

Abstract/Summary

This background paper explains the importance and guides the implementation of human rights-compliant, inclusive leadership and governance in health. It has contributed to the WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030. The report summarises evidence for the implementation of four key recommendations: 1) persons with disabilities must have accessible information about and access to the services they need, 2) persons with disabilities must be central to decisions about the services they receive and involved in the leadership, governance and evaluation of health services, 3) persons with disabilities have the right to have their health services provided through the most effective mechanisms of service delivery, including access to different disciplines working collaboratively through the most effective means of teamworking, and 4) people providing services within health and social care settings also have a right to work in safe working environments, where they feel valued, have secure employment and feel empowered to question each other and to advocate for the rights of service users. This report also provides an assessment tool which can be used to evaluate the extent to which services fulfil the above requirements. In identifying these four right-based recommendations for leadership and governance, this report contributes to enacting the recommendations of the WHO Global report on health equity for persons with disabilities (2022), the WHO Health Systems framework (2007), and to achieving Sustainable Development Goal 3 on 'Good Health and Well-Being'.

1. Background and context

According to the World Report on Disability, about 15% of the global population has a disability, representing approximately 135 million people in the WHO European Region. The rights of persons with disabilities are protected and promoted by the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which is the most swiftly ratified human rights treaty by Member States to the United Nations.

The Convention follows decades of work to change attitudes and practices relating to persons with disabilities. The Convention asserts the need for seismic change away from viewing persons with disabilities as “objects of charity, medical treatment and social protection, towards viewing persons with disabilities as subjects with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society” (UNCRPD, 2006). Rights-based changes are required at programmatic, organizational, systems and policy levels in order to ensure that policies, programmes and services fully uphold the human rights of all persons with disabilities and are developed in close consultation with organisations of persons with disabilities (CRPD Article 4).

The health sector bears a unique responsibility in this regard. Indeed, persons with disabilities have higher healthcare requirements, on average, compared to the broader population (WHO and World Bank, World Disability Report, 2011). Whilst they require access to the same range of general health services as the rest of the population (such as vaccinations and sexual and reproductive health services), persons with disabilities may need access to specialist services and goods related to their disability (such as specific medication, surgery, assistive devices and rehabilitation). They are also more likely to develop further health conditions resulting from their disability (for example, a greater risk of cardiovascular disease for persons with mobility impairments who find it difficult to exercise) and have greater unmet health requirements (such as lower access to preventative care). And despite their greater health requirements, persons with disabilities face barriers in accessing healthcare and, consequently, they have less access than others. These barriers include financial barriers; physical barriers related to infrastructure, equipment and transportation not being accessible; communication barriers, such as health information not being provided in accessible formats; and attitudinal barriers, including discrimination and lack of knowledge on disability issues amongst health workers (OHCHR, Policy Guidelines for Inclusive Sustainable Development Goals : Good Health and Well-Being).

Reforming leadership and governance is therefore an essential part of transforming the health sector and ensuring accountability so that all persons with disabilities can enjoy their right to the highest attainable standards of health. The aim of this background paper is to contribute to the WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030; and in that context the required action to achieve implementation of a rights-based approach to building Leadership and Governance: promoting compliance with the UNCRPD.

1.1 About the European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030

The World Health Assembly Resolution (WHA 74.8, 2021) urges Member States to realize the highest attainable standard of health for persons with disabilities, by ensuring access to effective health services; equal protection during health emergencies; and inclusive cross-sectoral public health interventions.

The WHO Global report on health equity for persons with disabilities, adopted in 2022, demonstrates that while some progress has been made in recent years, the world is still far from realizing this right for many persons with disabilities who continue to die earlier, have poorer health, and experience more limitations in everyday functioning than others. These poor health outcomes are due to unfair conditions faced by persons with disabilities in all facets of life, including in the health system itself. The report sheds light on the critical role of health leadership and governance, and entails 10 related targeted actions: 1. Prioritize health equity for persons with disabilities. 2. Establish a human rights-based approach to health. 3. Assume a stewardship role for disability inclusion in the health sector. 4. Make international cooperation more effective by increasing funding to address health inequities for persons with disabilities. 5. Integrate disability inclusion in national health strategies, including preparedness and response plans for health emergencies. 6. Set actions that are specific to the health sector in national disability strategies or plans. 7. Establish a committee or a focal point in the Ministry of Health for disability inclusion. 8. Integrate disability inclusion in the accountability mechanisms of the health sector, 9. Create disability networks, partnerships and alliances, and 10. Ensure the existing mechanisms for social protection support the diverse health needs of persons with disabilities.

In line with the WHO European Programme of Work 2020–2025, Member States should commit to specific actions and resourcing of disability-inclusive health systems, aiming to achieve equitable access to health regardless of an individual's disability. Inclusive health systems are critical to achieve universal health coverage, as envisaged in Sustainable Development Goal 3.

The WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030 envisions that, by 2030, persons with disabilities, through their representative organisations, will be fully included and considered in all health planning, delivery and leadership across the WHO European Region, leading to a disability-inclusive health sector and the promotion of the health and well-being of all persons, in order to achieve the highest attainable standard of health for persons with disabilities of all ages, ethnicities, and genders; and across the diverse contexts in the Region.

1.2 Key objectives of the European Framework for action

The objectives of the framework are as follows:

- Objective 1: Ensure that all persons with disabilities receive quality health services on an equal basis with others.
- Objective 2: Promote the health and well-being of persons with disabilities.
- Objective 3: Ensure that all health policies and programming, as well as resilience-building and recovery plans during public health emergencies, are disability inclusive.
- Objective 4: Build an evidence base on disability and health.

1.3 Overarching principles underpinning the European Framework for action

i. Human rights: Persons with disabilities should enjoy the same rights to health, employment, education, and all other areas of life on an equal basis with others.

ii. Universal design: The built environment, health equipment and products, and all health services need to be accessible and usable by all people.

iii. Life-course: The needs of persons with disabilities should be fully considered across the life course.

iv. Health systems: Actions need to be developed to ensure that disability inclusivity is integrated in the six building blocks of health systems: (a) service delivery, (b) health workforce, (c) health information systems, (d) access to essential medicines (and for persons with disability especially assistive technology products), (e) financing, **and (g) leadership and governance.**

1.4 Implementation and governance of the European Framework for action

Effective implementation at the national level will require strong political commitment to work towards a disability-inclusive health sector. This includes policy reform, resource allocation, funding mechanisms, the inclusion of persons with disabilities in all processes. It also requires the elaboration of detailed and measurable actions at all levels; from policy to service delivery to service user experience, in accordance with national and regional targets to be established during the European Framework process. Implementation of the framework will also require solid partnerships between organizations of persons with disabilities (OPDs), Member States, WHO/Europe, academia, health professions, and national and international organizations, including the European Disability Forum and the European Association of Service Providers for Disability, at the subregional and national level.

Effective implementation of the framework will be through national disability-inclusion action plans, with clear strategies and mechanisms to accomplish agreed national and regional targets. National action plans, which will include clearly defined priority actions, timelines, and resources, will be elaborated with the support of national, regional, and international stakeholders, assisted by WHO/Europe.

For the successful delivery of the framework, Member States will need to:

i. recognize the health inequities experienced by persons with disabilities, including through investing in collecting data and evidence.

ii. Show leadership through setting up a coordinated approach to policy development, implementation and monitoring, involving authorities at all levels, health service providers, civil society, households and individuals

iii. include persons with disabilities and their organizations in all processes and decision-making.

iv. ensure mobilization and allocation of sufficient resources

v. act, in partnership with persons with disabilities and their organizations, to implement the actions in this framework.

Through this framework, WHO Europe will seek alignment with and set itself to support the effective realization of commitments under the UNCRPD, the SDGs (in particular SDG3), and recommendations from the WHO Global report on health equity for persons with disabilities. It will also contribute to other relevant policy documents/ commitments in the region, such as the European Strategy for the Rights of Persons with Disabilities and its associated “EU Framework on Social Services of Excellence for Persons with Disabilities, the EU Care Strategy, or the EU Global Health strategy 2022

2. Rights-based Leadership and Governance - Promoting Compliance with the UNCRPD

In the above context, Ireland as a Member State is leading this aspect of the work and has convened a group of key stakeholders composed of people with appropriate expertise, including lived experience of disability (Annex 1). In the first instance, this paper aims to provide a foundation and supporting recommendations upon which to build an implementation tool for rights-based Governance and Leadership and promoting compliance with the UNCRPD.

2.2 About Rights-Based Leadership and Governance

Within the World Health Organization’s building blocks for health systems strengthening, the functions of governance and leadership are charged with ensuring that “strategic policy frameworks exist and are combined with effective oversight, coalition-building, regulation, attention to system-design, and accountability” (WHO, 2007). Four themes run through the subsequent evidence and arguments outlined in this paper:

First, persons with disabilities must have accessible information about and access to the services they need, including access to the same range, quality and standard of free or affordable health care and programmes as provided to other persons, on the basis of free and informed consent.

Second, people with disabilities must be central to and involved in the leadership and governance of health services.

Third, persons with disabilities have the right to have their health services provided through the most effective mechanisms of service delivery, including access to different disciplines working collaboratively through the most effective means of teamworking.

Fourth, people providing services within health and social care settings also have a right to work in safe working environments, where they feel valued, have opportunities to share leadership of teams, have secure and fulfilling employment; where they feel empowered to question each other and to advocate for the rights of service users.

Changing Health Systems

This paper focuses on health systems in the context of access to health services by people with disabilities , including both access to the same range of general health services as the rest of the population and access to specialist services and goods related to their disability. In different European countries “health systems” may incorporate or interact with social services, social care and welfare services to different extents and in different ways. This paper is written in cognisance of the *European Strategy for the Rights of Persons with Disabilities* and its associated “EU Framework on Social Services of Excellence for Persons with Disabilities”, currently in draft form, and discussed at the European Association of Service Providers for Persons with Disabilities (EASPD) Consultative Workshop, in October 2022, conducted as part of the development of this paper. While this paper focuses on leadership and governance as one of the 6 health systems building blocks, systems thinking acknowledges that what happens in one part of a system can affect others parts of a system. That is, things are interconnected, but not necessarily in a linear or direct, or a neat cause-and-effect relationship. Change can be mediated and moderated through different factors and pathways. Systems thinking therefore has to address the interactions within and between building blocks of health systems. A better understanding of the actions related to the right to health and associated rights, must permeate all ‘building blocks’ of the system, a point stressed in the European Disability Forum (EDF) Consultation Workshop, in November 2022, conducted as part of the development of this paper. Thus, building a framework of core competencies for rights-based leadership and governance needs to consider all components and levels of health services and the interconnectedness between building blocks of health systems (WHO, 2019, WHO, 2017, & MacLachlan and Scherer, 2018). At national level the Ministry of Health provides policy direction for health systems strengthening, while leadership to align disability rights with UNCRPD is provided by a far more distributed group of actors, including disability rights organizations. A synergy between these distinct types of leadership can be made possible through a collective approach to leadership and co-design (De Bruin et al, 2020; Hasselgren et al, 2021; Ward et al, 2018;) which is well suited to disability rights issues that require collective action, where no single organization can work towards UNCRPD compliance on its own.

Nothing About Us Without Us

Dainius Pūras, former UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, has highlighted the importance of addressing social and structural barriers for people with disability. Commenting on the work of this working group he stated: “Obstacles for implementation of the rights of persons with disabilities are no longer in bodies or physical or mental health conditions of individuals. Obstacles, which need to be removed, are now in the *physical, social or other environment, or they may be in attitudes of those who make decisions,* and in all members of the societies. To remove these obstacles is not an easy task, and it requires strong political commitment from Member states and the concerted efforts of all stakeholders, including civil society.“ (Pūras, 2022). He also suggested that “ there are continuing tensions between the principles of the UNCRPD and the strong reliance on a biomedical model, which continues to prevail in health and health-related services, and in the mindsets of many stakeholders“. Highlighting the importance of addressing power imbalances he states that „Usually in all levels of decision making, the opinion of medical doctors is considered to be most important, while the views of users of services, and also of non-medical professionals are considered to be less important. This may lead to the disempowerment of users of services and of non-medical professionals, and again, may become a serious obstacle to implementing the UNCRPD.“ (Pūras, 2022).

The fundamental idea behind the UNCRPD is equality; access to rights for persons with disabilities on an equal basis to persons without disabilities (Quinn, 2010). Whilst the UNCRPD articles are interlocking, some are especially relevant to the health service context: Article 5 on Equality and Discrimination, Article 9 on Accessibility, Article 17 on Protecting the Integrity of the Person, Article 19 on Living Independently and being included in the community, and Articles 24-26 on Education, Health, and Habilitation and Rehabilitation and Article 28 on Adequate Standard of Living and Social Protection. A discussion of each of these is beyond our scope here, but it is important within the ethos of the “Nothing About Us Without Us” moto of the disability movement, to consider Article 12 Equal Recognition before the Law, as this relates directly to ideas of leadership and governance in terms of the inclusion of people with disability in decision making. Article 12 recognizes the right to legal capacity of all persons with disabilities, including persons with psychosocial disabilities and intellectual disabilities. In the context of health, this means that forced treatment or hospitalization without free and informed consent are not supported by the UNCRPD, and are counter to it. Instead, practices should be promoted that respect the individual’s will and preferences (i.e. supported decision-making), based on accurate information, inclusive communication directly with the individual and respect for the right to refuse services, or make decisions which other may regard as unwise.

It is clear from the UNCRPD that persons with disabilities have the right to be involved in all decisions regarding their health, welfare and disability services and support .

This includes having a voice through shared leadership and governance of services that they use. Article 4.3 is also relevant to the present context in its assertion that it requires States Parties to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” regarding the development and implementation of legislation and policies, and Article 33 emphasizes the importance of people with disabilities being actively involved in such monitoring. Thus if people with disabilities are to be involved in the development, implementation and monitoring of national level policies, we should also expect this ethos to prevail in the design and leadership of services that directly affect them.

As recalled in the WHO Global Report on Health Equity for Persons with Disabilities, the lack of accountability mechanisms with proper monitoring and enforcement can lead to discrepancies between CRPD and its implementation, through uncompliant legislation or health service guidance, including those relating to disability allowances, clinical protocols and reasonable accommodation in clinics, hospitals, and other health services. In addition, limited accountability can be associated with acts of violence and abuse against persons with disabilities in health-care settings that are not properly reported or addressed. Persons with disabilities and their representative organizations are good sources to hold the health sector accountable for the implementation of disability policies. However, they are generally not engaged in governance processes, such as health sector planning, programme development and implementation. For example, women and girls with disabilities are rarely consulted on issues such as maternal and child health and wider sexual and reproductive health and rights. Persons with intellectual disabilities are often excluded from consultation processes due to negative assumptions about their capacity to contribute. Even when community groups are created with representation from persons with disabilities, they express concerns that when asked, their inputs are not fully considered by implementers. It is also important to bear in mind that for many persons with disabilities, the notion of healthcare or care “bears a heavy historical connotation associated with oppression and invalidation”. (Special Rapporteur on the Rights of Persons with Disabilities, A/HRC/52/32, para 28).

Leadership

Hughes (2009) stated that “Leadership has a range of definitions, but at its simplest it is concerned with the ability to influence others to achieve goals”. While individuals can be leaders, so too can groups of individuals be leaders. A significant body of research produced by the Centre for Creative Leadership and the King’s Fund, demonstrates that, “where leaders and leadership relationships are well developed, organisations benefit from *direction*, *alignment* and *commitment” (*see Eckert, et al, 2014; P2). In fact these two think tanks have contributed to the concept of collective leadership; meaning “ … the distribution and allocation of leadership power to wherever capability, expertise and motivation sit. The responsibility of leadership is shared by each and every member of the organisation” (p.1) And they emphasize that ``’A collective leadership culture requires new mind-sets, not just new skills.” (p1). In the context of disability, this requires a significant shift to prevent negative assumptions about persons with disabilities’ capacity to contribute.

A collective approach to leadership has been found to promote more effective team working, to enhance quality of care/service, to improve patient/service user safety and also to improve staff and service user satisfaction (De Brún et al, 2019). De Brún and McAuliffe (2020) using realist review methodology have empirically identified the contexts, mechanisms and associated outcome configurations (known as CMOCs) to promote effective collective leadership.

Collective leadership is part of the shift away from seeing leaders in terms of individual’s attributes, to seeing leadership as being a shared process between a group or team members (Nelson and Daniels, 2012). Distributed leadership is a type of collective leadership, wherein “leadership is exercised and shaped through interactions between formal leaders and employees with the sight set towards a common perception of collective influence” (p, 2: Hasselgren et al, 2021). Hasselgren and colleagues have extended this work into the disability and aging sectors and using a questionnaire and structured equation modelling approach across service providers in Sweden, they found that “…collaboration with responsible and trained staff, as well as active participation in development work aimed at promoting organizational trust and employee participation, were the most important conditions for managers to distribute their leadership” (p.8).

Interestingly the extent to which a strong sense of organisational governance is necessary for a collective leadership approach to work was also illuminated in this study: “managers’ experiences of poor organizational governance may in fact promote certain distributed leadership practices, since these potentially encourage leaders to seek support and guidance from their employees and imply an increased “room for manoeuvre” (p. 10). While good governance is clearly desirable, it is not always present and its lack should not necessarily deter the development of collective approaches to leadership.

There is potential for such approaches to have the benefit of enhancing employee commitment, satisfaction and overall team performance (see Quek et al, 2021); which may be of particular significance in making work in the health and social services sector more attractive. Even in the welfare sector of relatively well-resourced Sweden, there are high levels of sick-leave and employee turnover, and staff shortages are likely to significantly increase in coming years (Hasselgren et al, 2021) This led Hasselgren et al to argue that “organizational resource mobilization efforts must include measures to promote job attractiveness, engagement, and sustainable working conditions for trained staff” (p. 2), of which they see collective leadership as central.

The COVID-19 pandemic further tested health systems revealing disconcerting discriminations towards persons with disabilities. It also shed lights on overburdened and underpaid professionals, particularly women. For both people requiring services and people delivering services, current systems are struggling. Therefore rethinking tomorrow’s services requires taking a much more radical shift to co-produce solutions between all stakeholders concerned, including formal and informal support service providers and the diversity of citizens requiring their services, with particular attention to those most at risk of being left behind.

The cooperative approach to leadership recognises and draws on differences in knowledge, experience and practice according to what will best benefit the service user. To know this requires the service user to be a core member of ‘the team’, which is, after all, there to serve them. This is increasingly common in co-design approaches to health and social services for people with disability; incorporating direct service users themselves (Tucker et al, 2022) , family carers (Rathnayake, et al, 2021), and requiring new ways of working for staff (Harrison et al, 2021). The idea of service users co-leading the design of their own assistive technologies is also a core principle of the maker-movement (Holloway, 2019). Teams that provide the necessary skills, that embrace the centrality of the user's experience and needs, and work cooperatively and democratically will be best placed to provide rights-based leadership. The CRPD goes one step further by requiring that representative organisations of persons with disabilities are closely consulted in decision-making, positioning these as co-designers of the solutions that can lead to rights-based, accountable disability-inclusive health governance (and not only associating groups of selected users to occasional consultations on the quality of services).

Part of a cooperative approach therefore also requires a much more inclusive approach to leadership. Randel et al (2018) describe "inclusive leadership as a set of leader behaviors that are focused on facilitating group members feeling part of the group (belongingness) and retaining their sense of individuality (uniqueness) while contributing to group processes and outcomes" (p. 191). They also propose that those with stronger pro-diversity beliefs, with a greater sense of humility, and who accept higher levels of cognitive complexity (recognising and working with contradictions within individuals and groups) will be better inclusive leaders. Inclusive leadership requires being "able to create environments in which differences are valued and can be incorporated into the main work of an organization to enhance strategies, processes and overall effectiveness" (Chrobot-Mason and Roberson, 2021, p. 32). The WHO Toolkit on social participation in health recalls the importance of democratic governance of health, unpacks the role of civil society and the need to invest in their capacities to act as meaningful counterparts. Regretting the lack of opportunity for leadership from people with disability, Todd and Munroe (2021) argue that "positive disability leadership assets such as adaptability, creativity and problem-solving are not always celebrated, and that many disabled leaders feel that they need to hide their impairments in order to be accepted as a leader". The Shaw Trust's "Power 100" lists disabled leaders across different sectors, highlighting what disabled leadership "look like", providing role models for other people with disabilities and changing expectations of those without disabilities. Collaborative, inclusive and more cooperative approaches to leadership present new and overdue opportunities for people with disabilities to share leadership in their own and other’s health and social services.

Yet barriers remain that prevent OPDs from contributing to health governance and leadership, including: negative assumptions about the capacities of persons with disabilities to contribute (in particular persons with intellectual disabilities, persons with psychosocial disabilities), discriminatory laws denying legal capacity to some groups, lack of accessibility of health governance processes (including consultations, documents, meetings), limited resources of OPDs (including financial, time) and significant opportunity costs to engage. These need to be addressed by transforming power relations and mindsets within health to shift away from carer-dominated systems, setting up accessible and inclusive accountability mechanisms, ensuring accessibility and reasonable accommodation throughout all processes to enable inclusive, participatory leadership, and investing in OPDs to play meaningful roles as valued counterparts.

Governance

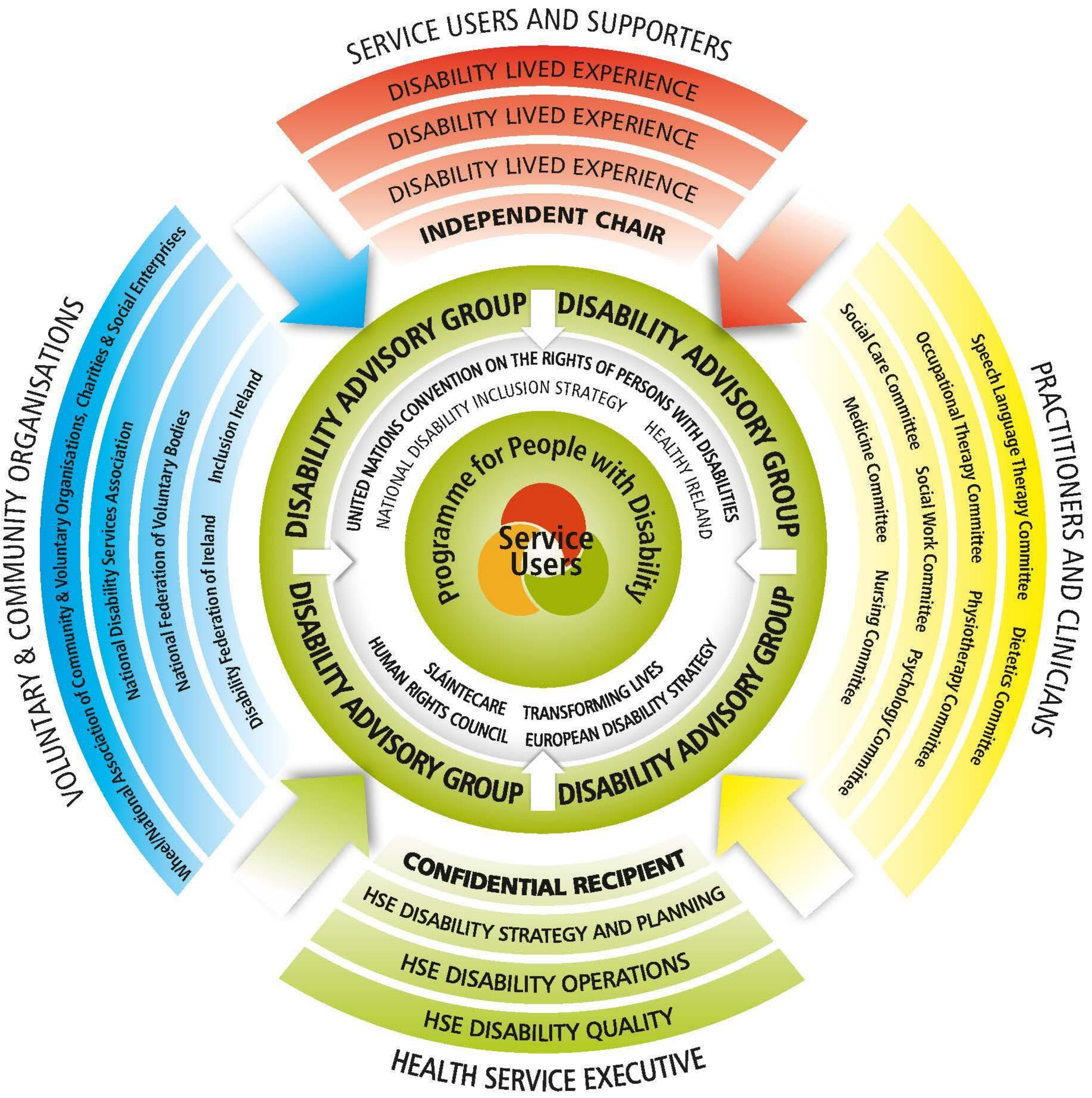
Brennan and Flynn (2013) reviewed 29 extant definitions of clinical governance and found that these incorporated a mixture of activities relating to governance, management and practice, which they argued, was confusing for those expected to execute such roles. Brennan and Flynn distinguished between three functions that are often conflated within governance in health settings – clinical governance, clinical management, and clinical practice. The Irish National Clinical Programme for People with Disability (NCPPD) definition of clinical governance, inspired by Brennan and Flynn’s definition, but aligned to the Irish service context is:

“the systems, structures, processes and standards through which health and social care teams, and others, contribute to and are accountable for the quality, safety and experience of service users in the delivery of services. Multiple individuals have important roles and responsibilities within an overall system of clinical governance; while there are lines of individual clinical responsibility, good clinical governance emerges from the practice of interlocking and integrated working throughout the system” (NCPPD, 2021, p6).

It is however important to acknowledge that it is the *process* of governance which is complex. Lim and Lin (2021) surveyed how health workforce governance is understood and concluded that governance in the health workforce remains poorly conceptualised. They do however assert the literature suggests “that governance represents the *efforts and processes* through which priorities are achieved. ‘Stewardship’ further adopts the additional element of *direction*, i.e. in defining an overarching vision, goal and ‘playing field’ (p.2). Lim and Lin suggest that rather than seeing governance at the national level as a “public policymaking affair effected primarily in a top-down fashion, an improved conceptualisation of health workforce governance sees the governance process as network-based and stakeholder-driven” (p. 5-6). They describe how “In this frame, governance refers not only to the *processes* through which responsibilities are distributed amongst different actors, but also the *relationships and connections* within a complex web of interlinked stake-holders wishing to influence the processes of governance” (p. 6, italics in the original), Lim and Lin also highlight the importance of “Stewardship against vested interests through institutional and regulatory reform where necessary” (p. 6).

As an example of recent experience in Ireland, the governance of the NCPPD is through a Disability Advisory Committee (DAC), which has been structured to be inclusive of service users, different types of service providers, a broad range of involved professions; as well as various aspects of the government provided national service; the DAG also has lived experience representatives and is chaired by a person with lived experience of disability. Figure 1 illustrates stakeholder involvement in the DAG. The approach to governance illustrated in Figure 1 (see https://www.hse.ie/eng/about/who/cspd/ncps/disability/ for more details) aligns with WHO’s work on Effective Health System Governance for Universal Health Coverage (UHC) (see: https://www.who.int/health-topics/universal-health-coverage/health-systems-governance#tab=tab_1). WHO recommends that three main categories of stakeholders interact with each other to determine governance: the State (government organizations and agencies at central and sub-national level); the health service providers; and the citizen. In the Irish context the citizen is embodied in the presence of service users on the DAG, but also organisations for persons with disabilities (OPDs) and organisations which advocate on their behalf, which are key to a rights based approach.

Figure 1: Representation of stakeholders and guiding national and international policy documents for the Disability Advisory Group of the National Clinical Programme for People with Disability (in Ireland).



THE DISABILITY ADVISORY GROUP STRUCTURE
with relevant groups of stakeholders and polices informing the work of the National Clinical Programme for People with Disability (NCPPD).

The relationship between Disability and Health services

In the Irish context of disability services the concept of these services being “clinical” is contested. However, the National Clinical Programme for People with Disability (NCPPD) is nested within a suit of other “clinical” programmes and so, presently, has this style of titular phrasing. It is important to recognise that many people with a disability have difficulties that do not require a medical or a clinical intervention. Many people with a disability do also have an associated health problem, for instance, a wheelchair user may develop pressure sores, or a person with cerebral palsy may have painful contractures; in such situations health interventions can be life-saving and pain relieving. For some persons with disabilities healthcare has a very important function (Shakespeare, 2013). However, it is not the case that everybody with a disability necessarily also has a disease, a disorder or a deficit of some type, and so it is not appropriate, or rights-based, to construct disability as though it is a health problem (MacLachlan, 2022; MacLachlan and Mannan, 2013), This makes the effective integration of health services and disability services both complex and of paramount importance. As the Missing Billion report (Kuper and Heydt, 2019) highlights “People with disabilities face higher healthcare needs, more barriers to accessing services, and less health coverage, resulting in worse health outcomes…” and a corresponding need to “… Ensure that all health services, programming, and trainings consider the needs of people with disabilities;” (P.2)

Different Member States partition the provision of services for people with disability in different ways, and often across several government ministries. Disability services may entail persons with disabilities still living in institutionalized settings, or they may live in group homes in the community with other persons with disabilities, or they may live independently, or continue living in the family home with family “carers”. In some Members states some persons with disabilities continue to live in Nursing Homes generally intended for much older people. Different types of respite services are available across Member States. Increasingly persons with disabilities living in the community can avail of a range of services and supports, such as personal assistants, home support workers, decision-making supports, personal budgets, advocacy support, the use of digital and assistive technologies and improved access to transport and housing. For those living in the community, Day Services may provide a range of recreational, supportive, or occupational training opportunities. Across Member States such services are provided by a range of health and social care professions, as well as cadre with shorter and more task-specific training and are managed through different government ministries in different countries. They also rely on services, such as accessible housing and accessible transportation, that fall within the scope of other ministries, requiring cross-sectoral collaboration.

A rights-based approach sees such services and supports as providing people with more capabilities by which they are empowered to make life choices (Mitra, 2006). However, there is no single profession for whom their skills are required for all people with disability, and for most people with disability they require one, or several, but very rarely all the professions that work in the disability sector. So how should we organize health and social care practitioners - where no single profession is always essential, but several different professions may be beneficial for some individuals, at least sometimes?

Traditionally the approach to disability services has been to organize on the basis that the person with a disability is diseased, disordered or in deficit; and therefore a so-called ‘medical model’ of service delivery has been used. Giving one profession authority, privilege and power has created many of the problems associated with the medical model – such as institutionalization and the over-prescription of medication (WHO, 2021). The shift to social and rights-based models of disability has led to disability being more often hosted within ministries of social affairs or equivalent. However, “While abandoning the medical model of disability does not mean rejecting the practice of medicine, medicine cannot be the gatekeeper for people with disabilities’ rights” (UNICEF, 2021).

Making Disability Teams Work

While many people with less complex disabilities may be effectively supported by single professions working in a primary care context, those with more complex disabilities will often benefit from availing of a team comprised of different professions. In a multidisciplinary team, practitioners often work independently, in parallel, with a service user, and team members come together to discuss their experiences. In an interdisciplinary team, practitioners work together - recognizing that there are often overlaps and intersections between their disciplines and that these should constitute part of integrated services and supports. In both cases the service users should also be centrally involved in discussions about them – “nothing about us without us”.

If team-based interventions are an important mechanism for providing services and supports, then such teams must work as effectively and efficiently as possible. In essence this requires us to consider – independent of specific services or supports – what is the best way for teams to operate? If teams are the central mechanism to deliver services and supports, then teams that do not work well jeopardise both the benefit to an individual service user and represent an inefficient and wasteful use of resources for service providers.

Optimal Teamworking

Wei (2022) synthesis of the results of 36 systematic reviews of interprofessional collaboration found that successful collaborative teamwork arises through a process of first, personal relationship building between individual workers, next working together and then identifying how to actively collaborate through their work. Wei (2022) emphasize that effective collaborations benefit all stakeholders – service users (“patients”), service providers (“professionals”) and provider organizations – all benefit, each in turn.

Zajac et al (2021) review of the literature was based on the understanding that effective teamwork is a prerequisite for optimal, effective and safe “patient care”; and they therefore sought to create a team development framework to facilitate such teamworking. Interestingly they stress that “although teamwork has been integrated into core competency models of health professional education, there is still an imbalance with a stronger focus on individual skill development, individual contribution, and accountability “(p.2). Noting the benefits of teamwork in relation to a greater diversity of views and expertise, Zajac et al (2021) also states that “there are a number of challenges inherent to healthcare that can also hinder performance, including psychological barriers (e.g., professional silos, hierarchies, power differentials) and organizational barriers (e.g., distributed teams, hybrid working models)” (p.2). According to Weller et al (2014) “Recent evidence suggests that improvement in teamwork in healthcare can lead to significant gains in patient safety, measured against efficiency of care, complication rate and mortality”, and furthermore they hoped that improvements in teamwork in “healthcare may be the next major advance in patient outcomes.” (p.149). So there seems no doubt that the function of teams in health and social services is recognized as a decisive vehicle for effective service delivery.

Power Asymmetries

There are many areas that span across health, social and educational services - including, aging, child development, rehabilitation, and mental health - which employ a wide range of professionals who must interact in an integrated way for service users to benefit optimally. However, this requires multi- or inter-disciplinary teams to work as effectively as possible, incorporating often quite different viewpoints and skill sets. The way in which these teams are structured and operate matters greatly. Team members are more likely to speak up, voice contrary views and question orthodoxies in teams where there is a greater sense of psychological safety (O’Donovan and McAuliffe, 2020). Psychological safety is about feeling secure in taking interpersonal risks in, for instance, a workplace; such safety enhances willingness to contribute ideas and share concerns; it entails feeling comfortable to exchange information and knowledge (Edmondson and Lei, 2014). This contrasts with Fink-Samnick’s (2016) concerns: “The hierarchal culture often allowed to fester in health care organizations continues to be rampant—one fueling a passive atmosphere that enables bullying, as opposed to one empowering the needed change to combat it." (p 114).

Kearns et al(2021) recent systematic evidence review of the impact of power dynamics and hierarchies in healthcare teams incorporated 20 papers relating to power dynamics and team effectiveness and 19 papers concerned power dynamics and service user/patient safety. They concluded that power dynamics inhibits team communication, and in turn this inhibits team members from questioning senior colleagues, impacting the overall effectiveness of the team and service-user/patient safety. Some of the barriers to speaking up Kearns et al identified included deference to seniors, feelings of intimidation and powerlessness, concerns about reprisals and more general repercussions of speaking up. They also noted perceived poor self-efficacy, a lack of self-confidence and poor role clarity as deterring some team members from speaking up. Schmutz et al (2019) review of 31 papers which had themselves conducted meta-analysis across a range of health service domains, found that overall –regardless of professional composition, team familiarity, average team size, task type, and type of performance measure - teamwork has a significant effect on performance.

The Irish National Clinical Programmes recently held an event to reflect on learning from the experience of responding to Covid-19 and how that might contribute to a more resilient health service. Philip Crowley, the National Director of Strategy and Research, argued that "the flattening of the hierarchy promoted better decision making" and that it was important to hold on to this "more democratic approach" to create a more resilient system. Stephen Mulvany, Acting CEO, also stressed the importance of "distributed leadership" for resilience.

In line with CRPD Article 4.3, a more democratic approach to health governance requires active consultation with organisations of persons with disabilities (OPDs), who have a unique role to act as intermediaries and representatives of the diversity of persons with disabilities. Unlike individuals with disabilities consulted as services users, they have a unique mandate to consult and aggregate the collective voice and priorities of their constituencies. Meaningfully engaging OPDs and building their capacity to provide meaningful contributions is an investment in restoring agency to groups that have been historically discriminated against (Global Disability Summit (2022)

Discussion paper on Meaningful Engagement of Organisations of Persons with Disabilities and UNDIS (2019) Guidelines on Consultation with Persons with Disabilities) and necessary to address the power dynamics that are historically weighted heavily towards health professionals.

Returning to Dainius Pūras, a former UN Special Rapporteur and a medical practitioner, states that “ [T]he important principles of the UNCRPD are quite well presented in the national documents that guide the design and provision of health and health-related services for persons with disabilities. *However, when implementation starts, often these principles are not properly observed, and most often this happens because of power asymmetries (imbalances) and dominance of the biomedical model.* This is why it is of utmost importance to highlight the existing tensions when the tradition of decision making (driven by hierarchies) interacts with principles of the UNCRPD, and to continue to search for creative solutions, with the strong involvement of experts by lived experience.“ (Pūras, 2022).

WHO‘s Guidance on Community Mental Health Services (WHO, 2021), is a very promising step towards more person-centred and rights based approaches. Pūras concluded that “[T]he European region and the EU are in a very good position to take the lead in the process of abandoning the legacy of outdated attitudes and fully implementing the UN CRPD. Again, Leadership and Governance would be crucial issues in this process.“

Critical Thinking

Effective teamworking also requires practitioners to have the inclination and opportunity to reflect on and think critically about what they are doing and how they are positioned within the system of service delivery. This requires us to create practitioners who are able to think outside the assumptions, the models, the attitudes and the ‘loyalties’ of their guild. Unless we create such professionals and nurture a culture in which doubts are welcomed and questioning is valued, then there will never be real dialogue between service providers and service users, and their organisations. Critical thinking should be seen as a positive constructive force rather than being interpreted as anti-authority or knocking down knowledge systems; rather it is about opening spaces for real dialogue between across all perspectives (see Bracken et al, 2021 for a discussion in the context of psychiatry and mental health). Also, relevant here is the idea that "staff who do not feel respected or listened to will not provide good care" (Crowley, 2022).

Disciplinary Capture

Hierarchical structures also facilitate "disciplinary capture." Disciplinary capture is an important threat to address if a team is to work as effectively as possible. It refers to the way in which one discipline thinks about a problem, then influencing how other disciplines feel they ought to think about it (Brister, 2005). This may occur especially where one discipline has higher status, more power or great privilege than other disciplines working in the same team. For instance, the "medical model" of mental health sees depression as an "illness" associated with an underlying "disease" process. In this view, low self-esteem, negative mood and withdrawal from contact with others are called "symptoms" or "signs" (of the disease process), and these may be ''co-morbid" with fears of social encounters becoming anxiety, and the estimated likelihood of these experiences continuing being described as "prognosis". The use of such medical terminology channels the way people think about these mental health difficulties, and this includes how other disciplines think about them too. When power asymmetries exist between disciplines, those with less power may feel that it is implicitly understood that they should use similar terminology to be more accepted and seen as authoritative, authentic or professional, or just to acquiesce to more powerful team colleagues.

The reason why the language we use is so important is that it primes us to associate certain types of presumed causes with certain types of response to those causes. Thinking about depression as a biologically caused disease process privileges physical interventions (for instance the use of drugs or electric shock, physical restraint or involuntary admission) more so than interventions that serve to address psychological and social experiences of difference, stigma, disempowerment, family breakup, etc. (see MacLachlan et al 2021). Disciplinary capture has been a pervasive feature of the role of medicine across many interdisciplinary areas that now require fearless assertion of rights-bases principles and cooperative teamwork. It is a person-centered perspective that needs to predominate rather than any disciplinary perspective and the value of effective teamwork must be judged in terms of its ability to achieve the goals of the person with disability and to contribute to enhancing their quality of life. Pragmatically, service users seek appropriate, effective and timely services and supports and may not be too bothered about how they are provided, as long as they have an opportunity to have their say about them.

Moral Injury

Lamiani et al., (2017) systematic review identified potentially morally injurious events as embracing various organizational elements, such as a lack of support, or lack of respect, or lack of involvement in decision making. They also identified difficult collaborations between clinicians, and specific job characteristics such as excessive workload, and insufficient time for proper care being implicated. They also noted low levels of structural empowerment, psychological empowerment, autonomy, and poor access to occupational resources as contributing factors.

Lentz’s et al (2021) literature review understands the experience of moral distress or moral injury as resulting from “disconnects between personal core values, formal and informal organizational values, vocational duties, and expectations”. (p.1). In essence employees are tasked with carrying out or complying with actions which they feel to be inappropriate - against their fundamental moral values - and they feel bad about doing so.

Phelps et al (2021) outlined the implications of moral injury for clinical distress and occupational functioning. They identify a link between moral injury and anger, mediated by potentially morally injurious events (PMIEs) experienced as *betrayal* (from leaders, team co-workers, or the employing organization); *injustice* (where others violate one's own moral code); and *shame* (when one violates one's own moral code). They describe a cycle of moral injury and anger and its relationship to service providers developing mental health difficulties and a “psychological break with the organization” (p. 81). Such experiences clearly have implications for managing human resources and industrial relations, and fundamentally for the rights of workers to work in an environment where they feel free to voice contrary views and to express their moral values, without fear of consequences. In disability service this may mean, for instance, fearing to speak up against a powerful individual or to disagree with a treatment which embraces a different model of disability than the one you believe in.

From this brief review of some of the relevant literature regarding leadership, governance and teamwork, what recommendations can be made to provide services and supports in a manner which can most effectively uphold the rights and provide the best possible opportunities for service users, while at the same time recognising and upholding the rights or service providers? In essence these are not conflicting rights. Where service providers can work most effectively, service users have most to gain; and as stated earlier health services should not be "done to" people, but rather they should be part of the decision making, of leadership, of governance. Of course moral injury is not the preserve of service providers, and provocative suggestions, for example include a "Truth and Reconciliation in Mental Health Services" process to explore and address perceived injustices (Spandler and McKeown, 2017).

2.2 UNCRPD: exploring the challenges and opportunities of Governance and Leadership - key principles.

While the interacting nature of the UNCRPD Articles is extremely important, Articles 25 (Health) and 26 (Habilitation and Rehabilitation) are of particular relevance to governance and leadership challenges in health and social service delivery. It is recognised that health and social services are arranged differently in each Member State, but in generic terms, as relates to persons with disabilities, they may be considered to comprise:

i. services provided directly by disability services to persons with complex disabilities,
ii. services provided in cognate areas to persons with disabilities - which includes rehabilitation, mental health, children's and older people's services.
iii. other services persons with disabilities may use.

While the Working Group will be focused on the first two of the above areas, it is hoped that the outcomes will also have relevance to the third area. Table 2 below indicates some of the key challenges in providing a rights-based approach to health and social service for persons with disability, and some possible ways of addressing these which could contribute to identifying indicators for rights-based leadership and governance.

Table 2: Rights elements, problem statements and possible solution principles which could contribute to development of a tool for assessing rights-based leadership and governance.

Note: the draft below shall seek alignment with OHCHR Policy Guidelines for Inclusive Sustainable Development Goals on Good Health and Well-Being and related Article 25 Indicators.

#	Rights Element	Problem Statement	Solution Principle (Question for Assessment Tool[1,2])	WHO Framework Targets and indicators[1]
Engagement in Services for Persons with Disabilities				
1.	**Accessible information** - are persons with disability provided with information about services in a variety of accessible format?	Information that can be assimilated is the gateway to accessing services, but it may not be proved in a way that persons with hearing, vision, intellectual or other functional difficulties may be able to understand	Is information provided in a variety of formats accessible to the range of difficulties which service users experience? When, where and by whom? What formats are available? Does your organisation provide a list for checking off accessibility .: e.g. Plain language, Easy to Read, Sign Language, Video Braille, Large print	Target 1.1 Indicator 1.1.1.
2.	**Responsiveness –** where services are failing the health needs of persons with disabilities, what is being done about them.	Service provision occurs in a competitive context, with other demands on resources. Unless data is collected regarding unmet needs, how these are being communicated, and how people can better physically access services, such unmet needs will not be addressed.	Are the unmet needs of persons with disabilities identified and recorded? Are people given an explanation if a service cannot be provided to them? Are travel routes and expenses to health facilities identified and facilitated as part of the health service provision?	Targets: 1.1, 1.5, 2.3, 4.1 Indicators: 1.1.2, 2.3.1, 4.1.1, 4.1.2

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[1] See https://www.who.int/europe/publications/i/item/WHO-EURO-2022-6751-46517-67449 for a copy of the WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030

3.	**Consultation** - are persons with disabilities involved in all formal discussions concerning the services and supports they personally receive?	Services for persons with disabilities may be delivered in a paternalistic or charity manner, or where experts or powerful others assume that they know what is best for the person with disability.	Are service users (or their nominated representatives) engaged to participate in all meetings concerning their services? Are they provided with choices aligned to their will and preference, with reasonable accommodations, access to information, support for decision-making where necessary and other commitments taken into account in scheduling discussions?	Targets: 1.1, 1.2, 1.4 Indicators: 1.2.1, 1.2.2
4.	**Person centred** - are services and supports person-centred, relevant to the context the person lives in, is the person involved in planning them, are services co-produced by the person and actually of service to them?	Service provision may be service-centric where people are expected to fit in with the priorities of service programmes, or of professions. Options to provide services at a community level mobilizing community support systems may not have been fully explored. Specific considerations, preferences and access requirements related to a person's disability may be overlooked.	Is the determination of a person's services based on their own strengths and support needs, their context, their preferences and direction, where provision is then configured around these and fulfils obligations under the UNCRPD (especially re Article 19 - Living independently and being included in the community)?	Targets: 1.1, 1.2 Indicators: 1.2.2
5.	**Decision making** - some persons with disability are denied representation of their views and	In many contexts decisions have been made by others – such as courts, parents or institutional authorities – rather than by persons with disabilities themselves; resulting	Is there enacted legislation and established protocols on Supported Decision Making which staff have been trained in and use; including the option for independent third parties to	Targets: 1.1, 1.2 Indicators: 1.2.2

	opportunities to indicate their decisions.	in disempowerment, infantilising and undermining of the right to self-determination.	support decision-making, and is this available on a daily basis, if required? Are involuntary treatment and institutionalisation clearly prohibited?	
6.	**Service Needs identification** - Is the provision of services and supports based on identified need and adequately resourced?	The allocation of scarce resources may be determined by the strength of advocacy groups, political pressures, or professional interests, rather than on the basis of greatest need.	Are resources allocated throughout the disability system in a manner that supports the identification of greatest need, including consultations with organisations representing the diversity of persons with disabilities and other disadvantaged groups?	
7.	**Procurement –** Are decisions about types of services and products to be procured made with input from persons with disabilities and their representative organisations?	Products and services may be procured at local or national levels without input from those who will use the services.	Are the views of the diversity of persons with disabilities represented in decision about the procurement of services, supports or products? Are accessibility standards and universal design mandatory requirements in health procurements?	Target: 1.1
Effectiveness of Service Teams for Persons with Disabilities				
8.	**Competency-based leadership** - where people are in leadership positions due to their abilities	Where formal leaders are appointed to teams these appointments are sometime based on a person’s professional training, rather than	Where formal leaders are appointed is this based on a match between identified necessary leadership skill sets and competency, irrespective of disciplinary background?	

	and established skills, rather than due to their profession or position.	their competency to complete the necessary leadership tasks.	Have leaders been trained on a rights-based approach to disability and participatory and inclusive management?	
9.	**Effective co-operation** within teams.	Teams are sometimes hierarchically based, with some people being referred to by titles and others by their first name; some people may also seek to dominate discussions, including regularly chairing discussions.	Are all members in a team referred to similarly (either all using first names or all using titles; Ms, Mr, Dr, Prof), is the team chairperson rotated between those who wish to take the role, is there a culture of co-decision making, mutual accountability and is the person with a disability considered to be part of their own team and having the final responsibility?	
10.	**Services provided by persons with disabilities**	There is an underrepresentation of persons with disability in service provision and leadership positions in services. This lack of diversity reflects both barriers to these positions and lost opportunities for improved decision-making in teams. The provision of disability services may benefit especially from people who have lived experience of disability.	What proportion of the workforce are persons with disabilities and are they employed to the same extent across different roles? Is there a policy to promote diversity of the workforce? Is there a reasonable accommodation policy?	Targets: 1.4, 4.2

11.	**Dominance** - the role of professional bodies, privilege, and power dynamics; and structures.	Some professional bodies have more influence or power than others, and this may deter them from engaging in compromise for the collective good; they may seek to exercise disciplinary capture or dominance.	Are there fora in which all professional bodies involved in services meet with parity of esteem and engage in collective problem solving?	
12.	**Governance** - are effective and fair governance arrangements in place?	Governance arrangement may not be clearly demarcated, and/or they may give disproportionate power to some professions or practitioners and fail to include the full network of stakeholders.	Are governance responsibilities clearly identified, and do they include input from all stakeholders, including persons with disability? Are conditions ensured to guarantee the meaningful participation of organisations of persons with disabilities in decision-making (including capacity building of OPDs, accessible and inclusive governance processes)?	
13.	**Diversity** - is representation in governance appropriately diverse and is this the case on decision-making committees?	In hospitals, in general community services, and in disability services there may be some degree of participation or persons with disability, but not always at the levels where decisions are made. There may also be barriers to representative organisations for persons with disabilities influencing governance processes.	Is there a diversity of persons with disabilities and other marginalised groups on the governing boards and sub-committees of hospitals, general community services and disability service organisations? Are conditions ensured, including accessibility and reasonable accommodation, for meaningful participation of all?	
Rights of Service Providers for Persons with Disability				

14.	**Worker Training** - are workers trained in a rights-based approach to services?	Workers who are unaware of the rationale, elements of, or examples of good practices in a rights-based approach to services are unlikely to be able to identify situations where rights are lacking, or to implement a truly right-based approach themselves.	What proportion of the workforce have undertaken formal training in a rights based approach, and at what levels of seniority? What spaces and structures are in place to ensure that they can learn from OPDs and partners to recommend rights-based transformation of services?	Targets: 1.1, 2.1
15.	**Worker Security** - do workers have security of employment?	Some workers in disability and health services are on precarious contracts where they have unreliable hours of employment, short-term contracts and low levels of pay. This may result in even well motivated workers feeling they must seeks employment in other sectors.	What proportion of the workforce are in secure employment? Workers should have contracts that offer the opportunity to be confident of ongoing employment, and at levels of pay that reflect the demands of their jobs and the needs of their clients to have a dependable and skilled workforce.	
16.	**Worker Advocacy**	Sometimes workers experience moral injury through having to be part of something they fundamentally disagree with; this may result in dissatisfaction, distress and disengagement from service colleagues and service users.	Do workers have a secure mechanism to voice concerns about leadership, teamwork, or governance; without fear of victimization and retribution, and do they feel heard so that they can	

			advocate for the rights of persons with disability.	
17.	**Worker career and skills development**	People working with few skill development or promotion opportunities, may feel less committed to their roles and career, and seek other work, resulting in high workforce turnover, which diminishes the opportunity for quality services.	Do workers, including workers with disabilities, have career pathways and skills development opportunities and does this apply to all levels of work?	

1. Author Note:

Possible Rating scale for responses to questions (with percentage indicators, where appropriate)

Not at All	(0%)
Rarely	(30%)
Sometimes `	(50%)
Usually	(70%)
Always	(100%)

2. Author Note

The structure of questions may alternatively be on a *maturity model* along a continuum allowing for progressive realisation. (see for instance https://www.ops.gov.ie/app/uploads/2020/07/Vision-Statement-Commitments-and-Maturity-Model-for-Public-Service-Organisations.pdf)

The above Table 2 may constitute a basis to evaluate the extent to which a rights-based approach exists in different states or organisations within a state. What might be regarded as “evidence” and which “implementors” should be used to demonstrate change will need to be considered at the country level. It would also be important to consider what would the UN Rapporteur look for, or the Committee on the Rights of Persons with Disabilities (CRPD) seek for alignment of the practice with a rights-based approach to leadership and governance, informed by the CRPD and its jurisprudence.

Annex 1

Members of the working group on a Rights-based Approach to Strengthening Leadership and Governance in Health Services

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