

Changes in language about IDD, mental illness, disability in different countries in different languages

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Abstract

The use of language to construct and drive societal and professional approaches to intellectual and developmental disabilities have undergone significant change across the 20th and into the 21st century throughout Europe. The changes in political, professional and colloquial language reflect increasingly inclusive practices and recognition of human rights based approaches to people with IDD internationally.

Keywords

Language, Discourse, Disability, Official Language, Colloquial Language.

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Introduction

Disability is a heterogeneous, complex phenomenon that manifests itself in various areas, numerous definitions emphasize the inability to perform social roles by people affected by disabilities as well as a limited possibility of participating in cultural and social life or working and existing independently (Kotowski, 2008) and from an international perspective there have been many debates about the terms used to construct and understand intellectual and developmental disability (IDD) (Schalock et al, 2007; Sherrill, 2010) and reframing of societal attitudes is critical to ensure positive change (Scior & Werner, 2015). For the most part, there is now a shared global understanding and definition of IDD (World Health Organisation 2016), and while different terms are used and often used interchangeably, it is critical that a consensus of the definition is provided.

As IDD is a life-long condition, and to improve Quality of Life (QoL), health, education and social outcomes, the approaches of supporting people with IDD have improved considerably, both globally and internationally.

“Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development” (WHO, 2016).

Critically, and irrespective of which term is used to define IDD, labelling an individual with an IDD can be multifaceted. On the one hand, access to appropriate supports, financial remuneration, and appropriate education may be easier to access once a diagnosis has been confirmed. On the other hand, a label may lead to stigma, exclusion or even segregation (Skundeberg, 2019; Lejzerowicz, 2020).

Here, the discourse and language attributed to disability will be explored across the contexts of 5 European countries throughout the 20th century. How does this discourse relate to the empowerment of people with IDD, does language drive change towards social inclusion or do social movements towards reduced stigmatisation and inclusivity facilitate changes in language across professional groups.

1. Changes in language about IDD, mental illness, disability in United Kingdom and the Republic of Ireland

Prior and up to the 1950's, terms such as 'idiots', 'fools', 'imbeciles', and 'mental retard' was the language used to describe people with IDD and were well-known and referred to across legislative and political agendas. These terms and others like them, often associated with negative connotations, dominated the disability landscape for many decades (Russell et al, 2005). Fortunately, and within a more inclusive and evolving society, these terms no longer feature in the language of disability as they are now deemed to be discriminatory and derogatory terms against people with IDD. However, young people today with IDD can experience high levels of stigmatisation and are often ostracised by their peers (Maguire, Wilson and Jahoda, 2019).

By way of background, these negative perceptions were often founded on ‘societal fears, intolerance, ambivalence, prejudice, and ignorance regarding disability’ (Marini, 2011). Additionally, these considerable negative societal fears and poor attitudes led to further exclusion and segregation as people with IDD were perceived widely as non-productive members of society. To this end, the 1913 Mental deficiency act, empowered families and carers to request institutionalisation, if a person was deemed to fall within four categories: idiots, imbeciles, feeble minded persons and moral imbeciles (Shutterworth, 1913). These views unfortunately continued over the decades and were fuelled by the belief that people with IDD could not contribute effectively to the political, economic, or social values expected of Western society at that time (Schalock et al, 2007). Consequently, people with IDD were perceived as ‘less equal’ and devoid of the same rights as their peers in the general population. The lack of social value of people with IDD meant that they were often held in the same esteem as criminals, people living in poverty and sex workers, who were also considered as deviant (Atherton, 2011). This negative view personified how people with IDD were treated and the UK and Ireland’s history, especially in the 19th and early 20th century (Gates & Mafuba, 2016; Kilgannon, 2021), and led to wider segregation, exclusion, inequalities and disparities across health, education and social care settings and services culminating in substandard and inappropriate care across the continuum of caring. It was not until 2007, in the United Kingdom (UK) that the term “learning disability” and “severe learning disability” were introduced into the Mental Health Act in 2007 (Gates & Mafuba, 2016).

Today, there has been a significant and welcome shift to human rights-based approaches, legislation and policies inclusive of people with IDD, which has led to a more appropriate and person-centred focused philosophy of care for this population group and their families. Specific European and UK legislation that has been pivotal in changing the disability landscape and included key legislations and policies such as the United Nations Convention on the Rights of Persons with Disabilities (2006), The Mental Health Act (2007), Valuing People (2000) and the Equality Act (2010) to name but a few. For example, the Equality Act (2010) is underpinned by antidiscrimination practices and protection for people with disabilities, including those with IDD and their families (Government, UK). This Act also ‘provides protection for carers, friends and family members of a disabled person by stating that people cannot be directly discriminated against or harassed because of their association with a disabled person’.

Currently, in the UK, the term ‘learning disabilities’ is the preferred term in use (Gates & Mafuba, 2016) while ‘intellectual disabilities’, is the preferred term used in the Republic of Ireland. According to Gates and Mafuba (2016) there are similarities between the UK Department of Health, (2001) and the World Health Organisation (2016) definition of IDD. As can be seen, these two definitions, clearly do not suggest that it is the ‘fault’ or within the remit of an individual that they have a reduced ability to understand or learn. Nor do either definition suggest that the IDD can be cured. Rather, it recognises that IDD will affect the individual across the life span.

‘A significantly reduced ability to understand new or complex information (impaired intelligence), to learn new skills with reduced ability to cope independently (impaired social functioning) which started before adulthood with lasting effect on development’ (Department of Health, 2001).

Not only have the UK and Ireland committed to moving away from institutionalised care to care based at home and in the community (Department of Health, 2012; Health Service Executive, 2011; Scottish Executive, 2000), these jurisdictions have also moved care solely from a medical model of disability discourse to a biopsychosocial model of disability. This move has garnered extensive debate and discourse in the disability arena and the dominant and most used models of disability include the medical model, the social model, and the biopsychosocial model of disability (Petasis, 2019), models which have helped to reframe our understanding of IDD from a UK and Irish perspective. The medicalisation of IDD within the UK can be traced back to 1845, when the Insanity Act placed a duty on all institutions providing care to implement the role of medical safeguard (Richardson, 2005). The recognition that the traditional medical model of disability was based on the premise of a ‘cure’, is now an outdated perspective as this model of disability suggests that it was within the ‘gift’ or ‘ability’ of the individual to be cured and they contributed to their own ‘negative’ social circumstance and situation. Consequently, and from a narrative of rights, inclusion, choice, independence normalisation and social role valorisation (Department of Health, 2001; Wolfensberger, 1983), there has been a considerable reframing of the construct and understanding of IDD.

2. Changes in language about IDD, mental illness, disability in Norway

During the period and after World War II, several terms were used to describe people we would now consider as having IDD, such as idiots, imbecilic, minus variants, oligophrenic and mentally handicapped, mentally retarded, weak ability and mentally disabled (Fjermeros, 2014). These terms are no longer accepted, neither scientifically nor politically. The most common term until IDD became the dominant term was “mentally weak” (Norwegian “åndssvak”). The first time the term IDD was used in Norwegian media was in 1964 when the Norwegian pediatric Johannes Sejerstedt Bødker wrote.

“The mentally ill - or the intellectual and developmentally disabled as I prefer to call them - should come under mental health care as a natural part” (VG 03.24.1964; as cited in Fjermeros, 2014, p. 152;).

The understanding and definition of disability has taken an environmental turn in Norway as it has in many other countries. Until 1967 the umbrella term used for disability until was “handicap”, however this term was understood to be too static and was replaced by the term “funksjonshemmet” in 1967 (Meld. St. 88 (1966-67), s. 3) which can be approximately translated as “functionally disabled” or “functionally inhibited”. This change in concept signaled an increased focus on disability as a result of societal barriers, rather than solely individual characteristics.

A major change in understanding came in a white paper in 1978 (Meld. St. 23 (1977-78)). This paper discussed the concept of disability as well as the societal norms which formed the basis for ideas of deviance and normality. A disabled person was defined as someone who

“as a result of lasting illness, an impairment or fault or because of social deviance, is severely limited in their practical daily life in relation to the society around him” (Meld. St. 23, 1977-78).

This definition of disability was further refined in 1998, shaping into what is often recognised as the gap-model of disability. The gap-model states that disability is the result of disparity between individual function and the expectations of social groups in order to attain self-efficacy (Meld. St. 8,1998-99). It is important to note that the gap-model is neutral as to what causes disability, instead disability arises when individual capabilities and societal demands do not match. It has been noted that the gap-model is especially well adapted to the Scandinavian welfare state systems, since it opens disability to "...the full spectrum of policy tools..." (Grue, 2014).

This understanding of disability is often called a relational understanding and is still dominant in Norway. The concept of disability, however, was discussed in relation to both the British social model of disability and WHO's classification scheme in a 2001 white paper (NOU 2001). This white paper suggested splitting or refining the term "funksjonshemming" into two separate parts. "Funksjonsnedsettelse" (functional reduction), was suggested as a term to describe the individual's physical, mental or biological impairment, while "funksjonshemmende forhold" (disabling conditions) describes the societal barriers to activity that a person with an impairment may meet (NOU 2001). These terms are commonly used in Norwegian official documents today.

Over the past decade the term citizen has been used by some disability interest groups (e.g. Uloba – Independent Living Norge, 2021). The purpose is to highlight individuality and human rights. The term citizens is used generically to describe all who receives welfare services, independent of diagnosis. However, the term citizens is seldom used by professionals.

3. Changes in language about IDD, mental illness, disability in Poland

In Poland the understanding and definition of disability has evolved since the 1950s, when the general term used to refer to disability was 'inwalidztwo', this can be translated to mean disablement. The term was used in medical, sociological, political and colloquial language for many years. For the purposes of retirement benefits, the concept of an invalid was used, defined as a person partially or completely incapable of performing employment due to permanent or long-term impairment of the body's fitness (Journal of Laws 1954, 30). Hulek (1969) emphasised the relational nature of disability stating that "invalidity" it was in comparison to non-disabled peers' capability to achieve within school, activities of daily living and employment.

Little changed regarding the attitude towards people with disabilities during the times of socialism. Disability was treated as embarrassing by the then authorities and was excluded from political discourse, however, the language relating to disability began to change and in the 1970s the concept of a disabled person ('osoba niepełnosprawna') developed. It should be noted this was not synonymous with the term 'invalid' with people with disabilities forming an intermediate category encompassing those who were not fully able but are without a formal, legal diagnosis (Giełda, 2015). Later, relational considerations of disability were further explored stating that disability was a condition affecting development and function, caused by deviance from physical, mental and social norms (Dykcik, 1998).

In the 1990s there was a growing tendency to oust inappropriate expressions such as 'an invalid' or 'a cripple' from language and in the field of social and vocational rehabilitation, the language of the disabled person began to develop, i.e. persons with a significant loss of

physical or mental abilities which restricted their ability to perform employment (Journal of Laws, 1991, 46). However, it was the Charter of the Rights of Persons with Disabilities (Official Journal of the Republic of Poland (Polish Monitor, 1997, 50) that generated significant changes in the language as well as the implementation of the rights of people with disabilities. People with disabilities were defined as individuals whose physical, psychological or mental fitness permanently or periodically hinders, restricts or prevents everyday life, study, work and social roles. Legal and customary standards advocated that people with disabilities had a right to live autonomously and free from discrimination (Polish Monitor, 1997, 50).

Defining disability, both in the social model and by the World Health Organization (WHO) not as a feature of an individual but as a multidimensional phenomenon resulting from the interaction between people and their physical and social environment as well as the effect of barriers encountered in the physical and social environment (WHO, 2001; 2009) has had a huge impact on the changes in the meaning of the term in the Polish language. Although the term ‘mental retardation’ still exists in medical science, it is inappropriate to use it for socio-political reasons. Similarly, the terms ‘mental heaviness’, ‘retard’, ‘imbecile’, ‘idiot’ have been replaced with the term ‘a person with intellectual disability (less frequently ‘a person with intellectual and developmental disability’).

The understanding of the concept of intellectual disability is also transforming. More recently emphasis has been placed on developmental capabilities, as well as the overall functioning of a person, not exclusively to the mental area (Ćwirynkało, Antoszevska, 2010). Increasingly, there is greater an emphasis on social model of disability, which looks to enable people with disabilities to gain control over their own lives (Pağowska, 2017; Twardowski, 2018; Lejzerowicz & Podstawka, 2020). The discipline of Disability Studies has also been established, offering a comprehensive view of the phenomenon of disability (Davis, 1997; Thomas, 1999; Walmsley, 2001; Wehmeyer, 2014).

More recently, the decision on how a person may want to identify in relation to disability should be a personal choice. Researchers indicate the conscious choice of a person with a disability in perceiving disability as a constitutive feature of their identity or one of the many features (Davis, 1997; Dunn, Andrews, 2015; Lejzerowicz & Podstawka, 2021) with some identifying themselves as disabled people while others - as people with disabilities (Liebowitz, 2015). The perception of disability is influenced by numerous factors, both personal and environmental. The use of inclusive language, postulated both in Poland and across the world, to define minority individuals or groups, is of significant importance for changes in the language and for creating a society without discrimination which is reflected by the language (Języki radykalnej wrażliwości (eng. The Languages of Radical Sensitivity), 2020; Guidelines for Writing About People With Disabilities).

4. Changes in language about IDD, mental illness, disability in Romania

Concerns about the “problem” of disabilities and mental illness experienced an intense development at the beginning of twentieth century Romania, especially in Cluj-Napoca, Bucharest and Iasi, the most important academic centers of the country - where American and European institutional and academic models were implemented. At this time, interest in the education of children with various disabilities increased, with the research and evidence base

having an applicative character and aimed at reaching an elementary level of social and professional integration. The predominant linguistic terms were “disorder”, “deficiency” or “abnormality”, as reflected in the preeminent literature (Kiss, 2013).

In the late 1940s and early 1950s, with the establishment of the totalitarian communist regime in Romania, the conceptual framework for the interpretation of disabilities was based more on psychiatric nosography. The term deficiency was often used, adopting a medical model of disability, assessed through clinical and paraclinical means (Gherguț, 2005). Given the deep ideological nature of the communist regime, in 1952 any explanatory model of disability and evidence from western academic sources was abandoned (Brătescu, 1994). The forced pronatalist policies that correlated population size with the economic productivity, and the lack of an official family planning framework, led to an increased prevalence of disabilities, for which services were not necessarily adequate (Gherguț, 2005). There was a period, until 1975 where concerns about services for children with disabilities intensified, particularly around the academic centers in Cluj-Napoca and Bucharest. However, in Romania the private practice of specialists in the fields of psychology or special pedagogy was forbidden, all services were conducted in few state institutions. In this context, there was some anachronism between research evidence and institutional practice with too few specialists and often a lack of professional intervention strategies). Many of the children with severe disabilities were abandoned and institutionalized in hospital dormitories and orphanages, where the conditions were totally inadequate, segregated away from their non or less disabled peers (Gherguț, 2005). For children with mild and moderate disabilities were the so-called "helping schools" - where the concepts of mental retardation (inadequate development), mental weakness (intellectual disability) and handicap (social and professional maladaptation due to disabilities) were most common. The concept of defectology (a term of Russian origin) was most often used in the case of sensory disorders, but the connotations were also attached to those with intellectual disabilities. For children with behavioral and deviant disorders, “correction schools” were established. Public policies as well as specialized works did not consider the disability within the social context. While there were certainly “courageous” approaches in both the field of psychology and psychopedagogy in a totalitarian regime, firstly, in 1975, some psychopedagogy departments (Preda, 2015) and then in 1977 psychology departments, were abolished within the Romanian universities (Kiss, 2013), instead promoting the ideology that communism led to the healing of disabilities (Miclea, 2000).

After the democratization of 1989/1990, gradually, the approach to disabilities and mental disorders aligned to DSM and ICD. A conceptual clarification was also proposed, with the re-establishment of special psychopedagogy programs within universities. The term handicap (most often used until 1989) was initially replaced by delay and deficiency in most (but not all) official documents, precisely because of the pejorative connotations. International terminology was generally adopted, concepts such as special education, special educational requirements (involving adapted and individualized strategies and programs), support services, equal opportunities (in relation with the allocation of educational resources and social opportunities) or normalization (in relation with need of intervention at contextual, social level) making their place in the vocabulary of specialists. After 2000, and especially after integration into the European Union in 2007, the terms social inclusion, early intervention and disability were most often used, especially among psychologists and psychopedagogues. Colloquially, the use of pejorative terms such “handicap” or “retard”

persists and there is some skepticism regarding the social inclusion of people with disabilities. Potential causes of these social perspectives is due to the insufficient resources allocated to inclusive education resulting in disparity expectation and potential achievement in many cases, however, there are awareness-raising and information campaigns at the level of public opinion and an increased interest on the part of professionals in terms of the quality of services.

5. International classification of functioning, disability and health

While changes to language across the included countries can be traced back to the mid-20th century, a turning point was the 19th resolution of the World Health Assembly in 1976. The final version of the classification was then adopted under the name International Classification of Impairments, Disabilities and Handicaps (WHO, 1980), and this would be amended to include contextual factors (environmental and personal) in the classification and renamed as the International classification of Functioning, Disability and Health. Most importantly, people with disabilities and disability organisations were involved in the whole process of building the new nomenclature. This was both groundbreaking and symbolic - people with disabilities 'got a voice' - they were able to have their say about the nomenclature used. The classification was accepted by WHO and recommended for use in across the globe. Importantly, the ICF assessed functioning and disability on a qualitative and quantitative scale and allowed for entries in both national and international languages in the form of electronic codes. The result was a tool not only statistical, but also with relevance across research, clinical care, education and for social policy purposes. Not only a usability a positive feature, but ICF also enhanced the potential to change social practices in terms of disability-related nomenclature. However, the 19th resolution did not immediately change the so-called everyday language practices in the countries analyzed in this article. The changes were evolutionary rather than revolutionary.

The changes in language regarding describing disability or mental illness show a slow but certain power shift in societies that become more critically aware of the power that language carries. Mwangi & Mwangi (2019, 56) writes that "discursive practices are social practices that are subjectively constructed with the objective of reinforcing relations of power in society". The way we see, and position people is socially constructed and reinforced by the power of naming. "The power of language is not only a power over others, made possible through language; it is also the even more pervasive power that language wields over the speakers themselves (Lavanya, Anjumkan 2021, 86)." On page 16 Odrowaz-Coates (2018) provides a comprehensive review of classic academic works dedicated to language and power. In her view language carries a strong but often implicit, not consciously realized power, to exclude or include certain groups or individuals, building social hierarchies and creating language driven social Imaginarium on where certain groups and individuals should belong in the social structure.

6. Conclusion

Intellectual, physical, developmental and mental disabilities, including those acquired as a result disease and injury, have always been a constant. Historically, the language used to describe disabilities has always had a significant impact on the way people with disabilities

are treated across cultures, political ideologies and religions. Until the 1970s the situation resembled a "tower of babel" - no common standards and language being used internationally to define and describe disability. What united the various terms was that they were stigmatizing and exclusionary. In the academic, professional and political discourse, as well as colloquially pejorative terms were the norm, dominating the field of disability for many decades (Russell et al, 2005) and framing disability within a medical model.

The change in language about disability is gradual, but in a more inclusive direction, initially within social policy, filtering through academic and professional language, before settling within every day, colloquial communication. In each of the countries explored here the term "disabled person" is more and more often replaced by the term "person with disability". This new terminology is of great - positive - importance as it is reflected directly in how a person is perceived and treated. Terms such as "disabled", "differently abled", "invalid" inextricably link the person and their characteristics. A kind of Goffmanian group stigma emerges, which marks the person as the bearer of the stigma (Goffman, 2005) leading to unjustified differentiation of rights and entitlements of these people.

Shifting the focus of the discourse from a disability a defining feature but to a characteristic reframes disability that interacts and exists within different environments. For example, a person with a visual impairment, in an environment rich in hands-free systems, Braille signage will be able to be considered an able-bodied person. The use of the phrase 'with disabilities' in the context of discourse created by and through language has a very significant and positive impact it informs social practice that constructs reality. In other words, language about disability not only represents reality but also constructs it. It is a powerful tool for domination and exclusion or emancipation.

Most importantly, an IDD label should not be used to define any individual. Rather, it should be used to identify the supports required to ensure that people with IDD are inclusive and valued members of society and can access appropriate supports as is their fundamental right. The discourse of IDD must be founded on person-centred and family-centred care approaches and improving QoL. Fundamentally, the common and shared practices of diagnosing and defining IDD as well as increasing positive experiences, comfort and competence of key stakeholders will inevitably assist health, education, and social care professionals to have this shared understanding of IDD from an international perspective for better lives for people with IDD and their families (Lipińska-Lokś, 2021; Smith et al, 2021).

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