I dati contano: un quadro conoscitivo della natura e delle criticità delle statistiche sulle persone con disabilità a supporto della loro inclusione

Data matter: an overview on the nature and criticalities of the statistics on persons with disabilities to support their inclusion

Serenella Besio
Università degli Studi di Bergamo – serenella.besio@unibg.it
Nicole Bianquin
Università degli Studi di Bergamo – nicole.bianquin@unibg.it
Mabel Giraldo
Università degli Studi di Bergamo – mabel.giraldo@unibg.it
Fabio Sacchi
Università degli Studi di Bergamo – fabio.sacchi@unibg.it

ABSTRACT
The *UN Convention on the Rights of Persons with Disabilities* (2006) stresses the importance of accurate, reliable, comparable and disaggregated data by conditions and areas of life. There is national and international research, but the UN itself declares them unsatisfactory, denouncing the connection with unequal and ineffective policies on disability. In light of these considerations, this paper intends to present an overview on the nature and criticalities of the statistics on persons with disabilities reviewing the scientific literature. Starting from this framework, the project «More than just numbers» disability data matter, held by the University of Bergamo, will be introduced. It aims at developing a theoretical-methodological model to promote an in-depth, updated knowledge on disability, on the phenomena and the systems related to it, as well as tracing political actions for a truly inclusive society.

La *Convenzione ONU sui diritti delle persone con disabilità* (2006) sottolinea l'importanza di dati precisi, affidabili, comparabili e disaggregati per condizioni e aree di vita. Esistono indagini e ricerche, nazionali e internazionali, ma l'ONU stessa le dichiara insoddisfacenti, denunciando la connessione con politiche ineguali e inefficaci sulla disabilità. È alla luce di queste considerazioni che il presente contributo restituisce un quadro conoscitivo della natura e delle criticità delle statistiche sulle persone con disabilità approfondendo la letteratura scientifica. A partire dal quadro costruito verrà introdotto il progetto "More than just numbers": disability data matter, promosso dall'Università degli Studi di Bergamo, con l'obiettivo di sviluppare un mo-

Formazione & Insegnamento XX – 1 – 2022
Codice ISSN 2279-7505 (on line) © 2022 Author(s)
Codice doi: 10.7346/-fei-XX-01-22_20

---

* The contribution was conceived, designed, and realized by all authors. The introduction and conclusions were written by the four authors, Mabel Giraldo wrote paragraphs 1, 2; Nicole Bianquin wrote paragraphs 3, 4; Fabio Sacchi wrote paragraphs 5, 6, 7. Serenella Besio supervised the entire article.

dello teorico-metodologico per promuovere una conoscenza approfondita, aggiornata sulla disabilità, sui fenomeni e sui sistemi ad essa correlati, nonché ingaggiare azioni politiche per una società realmente inclusiva.

KEYWORDS
Persons with Disabilities, Statistics, Inclusion, Participatory Action Research.
Persone con Disabilità, Rilevazioni Statistiche, Inclusione, Ricerca Azione Partecipata.

1. Processes of change of the population of persons with disabilities

Recent innovations in socio-health care (Bloom et al., 2011) increases the rate of life expectancy including the persons with disabilities (PWD) that according to WHO (2011) is about 15% of the world's population. In the last decades a profound change in disability understanding occurred calling for an afterthought of socio-educational and welfare practises according to the approach of *lifelong* and *lifewide learning*. An important contribution was given by the *Convention of the United Nations on the rights of persons with disabilities* (UNCRPD, 2006) which guarantees the affirmation of the rights and freedom of PWD by promoting individual autonomy, independence, choice and decision-making, not as rights linked to a specific condition, rather as the result of belonging to a wider group of equal citizens (Besio, 2020).

New cultural and epistemological models promote a radical overcoming of the custodial approach in favour of person-centred enabling approaches (AAIDD, 2015) such as the *capability approach* (Sen, 2005) and the *rights model of disability* (UN, 2006). These perspectives inspire an *emancipatory perspective* according to which PWD, regardless of their impairment, are considered no longer as objects of medical care, rather as active citizens who participate in and make decisions about their own social inclusion process (Bianquin, 2020).

However, this renewed vision struggles to be spread in society, both in the form of innovative policies, systems and services and in the dissemination of inclusive social attitudes. Sporadic concrete pilot experiences are carried out and, although interesting, they have not been translated into real models for practice (Abualghaib et al., 2019). Support services and housing solutions are largely considered unsatisfactory, and this increases the risks of isolation and impoverishment (Cappa et al., 2015), to the point of producing the «disappearance» of PWD from the official data. Moreover, as recognized by the international literature (Bianquin & Sacchi, 2020), the world outbreak has worsened those risks.

A weak and imprecise knowledge of these social phenomena gives rise to the implementation of conventional, short-sighted responses (Abualghaib et al., 2019). On the contrary, to implement solid and effective policies in this field it is necessary to count on explicit, solid frameworks for intervention as well as on precise data on PWD within the social context.

A new demographic model – that is the main goal and output of *"More than just numbers": disability data matter* (DDM) project[1] – could support a deeper

---

[1] It is a two-year project (2022-2023) held by the University of Bergamo and founded by Cariplo Foundation in relation to the call "Social And Humanistic Research For A Changing Society".

knowledge on PWD, their perceptions of quality of life, the modalities and quality of their participation in the socio-political fabric and overall in the civil life of their country; as well as on the causes of their «disappearance» from collective visibility and the solutions of survival or «hiding» they adopt.

2. Collecting comprehensive data for mapping changes and challenges

The importance of collecting data concerning PWD is mentioned in the art. 31 of the UNCRPD. These data must «be disaggregated into an appropriate manner, and [...] be used to identify and remove the barriers that persons with disabilities face in exercising their rights» (par. 2).

In 2011, the WHO noted that the mandate of the *Convention* was particularly urgent as «historically, there has been a lack of data on disability»[2]. In the same year the WHO promoted a worldwide survey, *World report on disability*, that pointed out that:

> «despite the magnitude of the issue, both awareness of and scientific information on disability issues are lacking. There is no agreement on definitions and little internationally comparable information on the incidence, distribution and trends of disability. There are few documents providing a compilation and analysis of the ways countries have developed policies and responses to address the needs of people with disabilities» (WHO, 2011:XXI).

In Europe, the need for statistical ongoing surveys involving the different life areas of PWD, is underlined: the very recent *Strategy for the Rights of Persons with Disabilities* 2021-2030 (EC, 2021) suggests the States of the Union to strengthen co-operation «on comprehensive and regular data collection» (EC, 2021:9) and to extend it on «areas such as accessibility, health and healthcare, employment, training, skills, education, social protection, poverty so that measures adapted to existing circumstances can be adopted» (*Ibidem*).

In Italy specific surveys are conducted by public and private entities (statistical institutes, ministerial offices, municipal and health administrations, associations, etc.) through various survey methods that are based on definitions of disability and categorizations that differ widely and are not always consistent with the field scientific literature. This leads to the availability of non-homogeneous data, difficult to compare or relate to one another.

The Italian Institute of Statistics (ISTAT; 2017) points out that:

> «the sources currently available, both administrative and direct, do not allow to identify with sufficient precision the number of beneficiaries of the intervention. The former (the administrative ones) are able to provide only the number of recipients of accompaniment allowances with details by gender, age and territory. The second (surveys) allow for a precise description of the family context of PWD and the type of help/assistance they receive but, due to the very definition of disability status, use different definitions from those adopted in Law 104/92 and referred to in Law 112/2016» (p. 5).

In addition, the diverse nature of the agencies involved in collecting data, together with issues related to the protection of privacy, often hinder the possibility

---

[2] https://www.who.int/activities/collection-of-data-on-disability (10/07/2021).

of initiating networking and mutual exchange of information, making it difficult, if not impossible, to know the life course of a PWD. Surveys on PWD are often collected in a discontinuous manner over time, with uncertain cadences and delays and published data are obsolete. These factors lead to incomparable data and provide a partial and fragmentary picture of the phenomena (employment, education, access to social and health services, etc.).

According to the *Report to the Technical Scientific Committee of the National Observatory on the Condition of Persons with Disabilities*, «statistical surveys continue to be the main tool for analysing the social inclusion of persons with disabilities because they are able to reconstruct their health and living conditions, family contexts and social networks» (ISTAT 2021:8).

Today Disability surveys should start from the definition of disability contained in the *International Classification of Functioning, Disability and Health* (ICF) (WHO 2001); its multidimensionality requires «collecting information on the accessibility of environments, transport, information and technology» (ISTAT 2021:5) and in general on the environmental factors.

Lastly, the same document stresses how:

> «in this historical phase […] the demand by decision-makers and political administrators for updated and complete data on this target population is becoming particularly urgent to identify the policies to be adopted, the planning of interventions and the organisation of services» (ISTAT, 2021:6).

3. Disability data matter

The importance of collecting data about PWD is a long-known issue. In 1988 the *United Nation Disability Statistics Database* (DISTAT) was established; in 2008, the WHO published the *Training Manual on Disability Statistics* (WHO, 2008) to provide operational indications on tools and data collection methodologies based on the bio-psycho-social model of disability (2001).

In 2011 the WHO published the *World report on disability* which offers «estimates of the prevalence of disability, factors affecting trends in disability (demographic, health, environmental), the socioeconomic circumstances of PWD, need and unmet needs, and the costs of disability» (WHO, 2011:21).

Availability of data on PWD is essential to obtain information on the barriers they encounter and which prevent their social participation. Several surveys showed that PWD are excluded across all arenas (Abualghaib et al., 2019) throughout the life-course (Groce & Bakhshi, 2019): for example, in education (*Global Partnership for Education* 2018), labour market (ILO & OECD, 2017), health and care services (Reed, Meeks & Swenor, 2020) with reference to the poorest and developing world areas. Data on women with disabilities are crucial to understand the double discrimination and intersectional inequalities they experience: they are more at risk of becoming disabled because of inequities in economic status and access to healthcare (Wheaton & Crimmins, 2016).

Without collecting data, the complexity and breadth of these phenomena cannot be grasped nor inclusive policy processes can be designed. The disability data gap is not just a question of a surveillance oversight; existing social injustices cannot be separated from this lack and inadequacy of information. Both perpetuate the exclusion of PWD from discussions and policies are data driven (Reed, Meeks & Swenor, 2020).

However data on disability are not small. A review of child disability measurement, carried out in 2015, identified 700 existing surveys or censuses from 198 countries asking questions on disability (Abualghaib et a.,l 2019). The same research showed that the number of surveys on PWD has grown during the time and the major data limitations concern data quality and comparability (Cappa, Petrowsky & Njelesani, 2015). This lack of consistent and good quality disability data in accessible forms limits quality analyses and progress evaluation (Altman, 2001).

4. How are data collected?

There is an increasing number of studies and statistics gathering data on PWD. However, collecting data on them represents a complex process with many critical issues (Altman, 2001). Currently no gold standards for its measurement exist and different frameworks and tools have been used to fulfil data needs. Understanding how these differences have influenced the measurement of disability is crucial to develop reliable and comparable measures (Altman, 2016).

Major challenges are due to a lack of consistent definitions and indicators of disability, combined with differences in methodologies used to gather data and quality of study designs (Cappa, Petrowski & Njelesani, 2015). The construct of disability itself has been defined and conceptualised in several different manners, often conflicting, and applied broadly across all cultural contexts (Schneider et al., 2009).

Usually PWD are categorised by impairment type; this mode is based on a medical model, wherein disability is seen as a consequence of disease and a restriction or lack of ability to perform or participate (Baglieri & Shapiro, 2012). This perspective considers only whether a specific impairment is present or not. Furthermore «utilising a list of impairments alone will result in the identification of only a small sub-population with more severe restrictions and not those with varying degrees of limitations, thus the overall picture of disability is incomplete» (Cappa, Petrowski & Njelesani, 2015:319).

The social model considers disability as the consequence of social barriers, policies, attitudes and cultures that marginalise the more vulnerable subjects, including those with disabilities. Following this conceptualization, some statistics focus on “handicap”, namely the measure of the socio-cultural limitations provoked by inaccessible and unfriendly societies (WHO, 1980). For example, in Italy some data are collected using the criteria of ‘legal disability’ expressed in percentage terms or non-self-sufficiency, as introduced at legislative level, respectively, by the Laws no. 68/1999 and no. 112/2016.

One of the most common methodologies to gather data is national censuses (Bruyère & Houtenville, 2006), that typically ask a single generic question to all members of a population. Another common methodology are general household surveys, including a module or set of questions on the disability status of persons. Other sources of disability data include administrative records, school-based surveys, key informant reports, and targeted disability surveys (Bruyère & Houtenville, 2006).

Each of them measures disabilities differently and has its own strengths and weaknesses. For example, national censuses that do not specifically ask about children have been found to be inadequate (Durkin et al., 1991); this is also recognized by the *United Nations Statistics Division* which stated that «the limited number of questions included in a census cannot provide a precise measure of the number of people with disability, especially among children (UN Statistical Commission 1997:94).

There are several atheoretical operational definitions, and only few based on theoretical developments. The reason for this might be that definitions in survey methodology tend to lag the theoretical developments (Altman, 2001). The challenge is how to identify persons who belong to the target group when the group is defined, not by their individual characteristics, but (fully or partly) by barriers in the environment (Altman, 2001).

5. The relevance of disaggregated data

The *United Nation Report on the Sustainable Development Goals* (UN, 2017) stated that the absence of disaggregated data for PWD worsens vulnerabilities and limits the understanding of the discrimination and exclusion faced by PWD. Data are needed to highlight where deprivation and disparities in inclusion exist. Disaggregating data, not only by disability but also by other characteristics such as, e.g., gender or income status, will reveal additional specificities that are vital for effective programme planning and for meeting the needs of the most marginalised people. In Goal 17.18, the *2030 Agenda* states that disability should be considered in addition to age, gender, income, ethnicity, race, geographical location and other relevant characteristics in a national context.

Reliable data are crucial to gain the trust of decision-makers and the wider community when supporting legislation, policies, funding, programming in national and international policy agendas in the direction of inclusion and participation of PWD (Albert, Dube & Riis-Hansen, 2005). Policy makers, programme staff and researchers need to monitor disability within a population and understand its trends, impacts and interventions designed to improve health and development (Durkin, 2001). Comparable statistics can also highlight national and international inequalities between different populations of PWD, for example by ethnicity, gender, age, region or type of impairment (Robson & Evans, 2003).

A study of the *Global Partnership for Education* (2018) shows that the lack of reliable disability data is a key barrier to the education of children with disabilities. In some countries there is limited information on their number, the percentage of those not in school, the type of school (special schools, mainstream schools), and the facilities available, including transports. Moreover, public authorities in these countries recognised that the lack of data prevented the identification of barriers to education for these children, as well as the planning and implementation of disability-specific programmes that could improve their well-being (Global Partnership for Education, 2018).

Estimating prevalence rates and disaggregating indicators by disability lead to identifying areas of exclusion and subsequently support monitoring and evaluating progress towards removing barriers. Ability of States to act on the implications of disability disaggregated data does not depend on mere political will, rather on budgetary constraints, which undoubtedly impact more significantly on low-income countries. Therefore, if there is no such data available, the political power to address inequalities towards PWD will be limited.

6. The numbers of PWD

In 2019 ISTAT published a survey *Conoscere il mondo della disabilità (Understand-*

ing the world of disability) providing a picture of the life of PWD in Italy. The following demographic description, focused on Italy, summarises, and analyses these ISTAT data according to the ICF, referring to specific domains of Activity, Participation, Environmental factors.

6.1 *Social, civic and community life*

ISTAT (2019) investigates social participation. Severe limitation seems to be an obstacle: only 9.3% of PWD frequently go to the cinema, theatre, a concert or visit a museum during the year. In the rest of the population the rate is 30.8%. Voluntary work, civic and cultural associations and political participation are the main forms of participation in political and social life. However, only 9% of PWD (as opposed to 25.8% of the rest of the population) are involved in one of these activities and they mainly choose voluntary work (6.3%) or associations (5.5%).

6.2 *Support and Relationships*

ISTAT (2019) follows that PWD have a much higher average age than the rest of the population: 67.5 compared to 39.3, 26.9% of them live alone, 26.2% with their spouse, 17.3% with their spouse and children, 7.4% with their children. The data collected show that more than 600,000 people with severe limitations live in a situation of severe isolation without any network they can rely on in case of need; 204,000 of them live completely alone.

6.3 *Attitudes*

Attitudes are a key element to ensure full participation of PWD. Although it is established that hostile attitudes can be barriers to inclusion, this aspect is not much investigated. In 2010, the *Serono Censis Foundation* conducted a survey aimed to deepen the knowledge on the ideas and perceptions of Italians regarding disability. No definition of disability was provided within the theoretical framework. A structured questionnaire was administered: it emerges that disability is perceived by most Italians as a limitation of movement, the 62.9% of the interviewees declared that they think first of all of this type of limitation, while the 15,9% think of a person with intellectual disability and 2.9% of a sensory disability. PWD mostly arouses positive feelings, solidarity (for 91.3%), admiration for their willpower and determination. But controversial feelings, embarrassment and discomfort are also common: 54.6% of Italians feel fear, for the possibility of one day having to experience disability in person or in their family. Working on social attitude appears to be necessary at present to fulfil the commitment to monitor the process of social inclusion of PWD provided for by Article 31 of the UN Convention and undertaken by all the signatory States.

6.4 *Services, systems and policies*

6.4.1 Education

The school surveys provided for by the *National Statistical Plan* are annually statistical surveys that manage the administrative information in aggregate form. The data are collected by type of disorder (intellectual, motor, visual, hearing and other) according to the *ICD Classification* by age. However, on the basis of a wide range of data, the achievement of equal opportunities for PWD in education is far from being achieved, despite some significant improvements. These improvements concern, for example, the number of pupils with disabilities enrolled in Italian schools, which increased from just over 200 thousand in the 2009/2010 school year to over 272 thousand in the 2017/2018 s.y.. Also the number of support teachers has increased: from 89,000 to 156,000. But the situation, as mentioned above, is still challenging. The rate of PWD who have reached the highest educational qualifications is 30.1% among men and 19.3% among women, compared to 55.1% and 56.5% for the rest of the population. Disability status exacerbates the differences: 17.1% of women have no educational qualification compared to 9.8% of men, in the rest of the population the rates are 2% and 1.2% respectively.

6.4.2 The labour market

The *Ministry of Labour and Social Policies* and the *Istituto Nazionale per l'Analisi delle Politiche Pubbliche* (INAPP - *National Institute for Public Policy Analysis*) are in charge of conducting statistical surveys on participation in the labour market of PWD. These surveys are conducted every two years using quantitative and qualitative tools to collect the data of PWD registered in the targeted employment offices throughout Italy. Registration is possible if a person has a certificate of invalidity; for this reason the population of PWD to which these surveys refer is made up of PWD and not all PWD. The concept of invalidity does not provide information regarding the types of disability. By the law, the only ones to be reported are the visual and hearing impairment.

6.4.3 Social and health services for disability

The offer of residential and non-residential services (ISTAT 2019) is in charge of 69,903 structures, 64% of which are non-profit institutions, 28.7% are companies and 7.4% are public institutions. There are considerable territorial differences: in the North-East there are 1.8 employees per 100 inhabitants, three times more than in the South (0.8 per 100 inhabitants). Residential services play a significant role. In 2014, they offered about 51 thousand beds, a decrease compared to 2010 of about 4,000 units.

7. The project *"More than just numbers": disability data matter*

In the ICF domains presented, there are still significant disadvantages for PWD compared to the rest of the population, despite the Italian legislation of the last 40 years. The impossibility of systematically collecting the characteristics of persons, contexts and projects, nullifies the opportunity of correlating them, leading to two unwanted outcomes: a) abandonment of the development of a self-determined life project, which is adapted based on existing services; b) impossibility to define intervention models, that might be disseminated into a new perspective of social inclusion and welfare protections. Therefore, even statistical collection is a long way off in Italy and throughout the world, data matter and play a crucial role in supporting a more complete knowledge of the living conditions of PWD in different settings and related barriers that determine their disadvantages.

To respond to this urgency of a new demographic model, the upcoming project, entitled *"More than just numbers: disability data matter"* held by University of Bergamo, aims at giving a valid contribution to the huge scope of developing a comprehensive model and a related device able to plan and manage at regional level (Lombardy) the collection of exhaustive and disaggregated data in the field of disability, crossing and connecting data relating to personal traits with those relating to social contexts. This will give the possibility to trigger innovative and inclusive design projects both at individual and system levels.

The DDM project intends to understand the demographic changes underway and to foster the development of a more inclusive and sustainable society for people and the ecosystem through the new model for collecting data.

Starting from an analysis of the statistical, demographic and administrative data on disability, at international/national/regional levels, the DDM project has two main goals:

1. developing and validating a new theoretical-methodological model for the analysis of the condition of disability, based on the ecosystem approach of the ICF able to plan and manage a collection of complete and disaggregated data and to trigger inclusive projects at the individual level / system;
2. developing and testing in Lombardy a prototype of a data management system related to the model, to be used at regional, inter/supra-institutional level, which allows to grasp, on a large scale, the complexity and specificity of the phenomenon and at the same time is flexible/modular to regional/contextual specificities and, therefore, transferable.

In this research project, a mixed research method will be implemented to produce an adequate representation of life of PWD. It will also adopt the participatory action research (PAR) intended as the active involvement, participation and action of members of end-user communities and stakeholders, including PWD. In PAR communities of inquiry, considered as co-research, evolve and address questions and issues that are significant: sharing objectives and co-constructing solutions will generate renewed collaborative networks (Reason, Bradbury 2008; Chevalier Buckles 2013).

8. Conclusions

This contribution highlights several criticalities on the statistics relating to PWD urging their rethinking in terms of data collection methods within a unique and widely acknowledged model of disability, based on the actual vision of disability as a relation among personal and environmental factors. On the operative side, this means obtaining shared, comparable, and reliable data based on the analysis of the authentic contexts of life of PWD.

Adopting these theoretical and methodological approaches, DDM project should provoke a truly "copernican reversal". Since until now the users' needs are collected – and searched – according to the areas of influence of the various edu-social-health systems involved and to their formal constraints and possibilities, bringing to fragmentation of the interventions, responses "on demand", loss of a global vision and dispersion of financial resources (Dube et al., 2005). Considering the life of PWD as a set of unfitting puzzle pieces provokes, at the level socio-political system, the loss of awareness of the global situation and reduces its interventions to a set of "stopgaps". On the contrary, the ecosystemic approach - as that adopted in DDM research - leads to a new cohesion and collaboration between the different edu-social-health agencies favouring sharing of visions and unity of purposes based on aggregated and disaggregated data, and flexible enough to represent the persons' lives, the individual and environmental characteristics, along the different life areas and times.

The pivot of this new demographic model will contribute to develop a deep, updated and comprehensive knowledge and culture on disability, on disability-related phenomena and systems, as well as to direct at new mainstream (national and local) policies towards a truly inclusive society (Abualghaib et al., 2019). Moreover, adopting PAR, these goals are achieved involving some selected and crucial stakeholders that represent authoritative voices in the social and political debate at national and local level.

References

Abualghaib, O., Groce, N., Simeu, N., Carew, M.T & Mont, D. (2019). Making Visible the Invisible: Why Disability-Disaggregated Data is Vital to "Leave No-One Behind". *Sustainability*, *11*, 3091-3099.

Albert, B., Dube, A. K., & Riis-Hansen, T. C. (2005). *Has disability been mainstreamed into development cooperation*. London: University of East Anglia Press.

Altman, B.M. (2001), Definitions of disability and their operationalization, and measurement in survey data: An update, In S.N., Barnartt & B.M., Altman (Ed.) *Exploring Theories and Expanding Methodologies: Where we are and where we need to go* (Research in Social Science and Disability, Vol. 2), pp. 77-100, Bingley: Emerald Group Publishing Limited.

Besio, S. (2020). Autodeterminazione: principio o diritto, fra individuo e società. In Giraldo M. (2020). *Verso un'identità autodeterminata. Temi, problemi e prospettive per l'adulto con disabilità intellettiva* (pp. 9-19). Milano: Guerini e Associati.

Bianquin, N. (2020). *L'ICF a supporto di percorsi personalizzati lungo l'arco della vita*. Lecce: Pensa MultiMedia.

Bianquin, N. & Sacchi, F. (2020). Disability&Covid-19: a framework for actions from international documents. A thematic analysis in a scoping review. *Nuova Secondaria Ricerca*, *2*, 617-650.

Bloom, D. E., Boersch-Supan, A., McGee, P., & Seike, A. (2011). Population aging: facts, challenges, and responses. *Benefits and compensation International*, *41*(1), 22.

Bruyere, S. M., & Houtenville, A. J. (2006). Use of statistics from national data sources to inform rehabilitation program planning, evaluation, and advocacy. *Rehabilitation Counseling Bulletin*, *50*(1), 46-58.

Cappa, C., Petrowski, N. & Njelesani, J. (2015). Navigating the landscape of child disability measurement: A review of available data collection instruments. *ALTER Eur. J. Disabil. Res./Rev. Eur. Rech. Handicap*, *9*, 317–330.

European Commission (2021). *Strategy for the Rights of Persons with Disabilities 2021-2030*. Bruxelles. https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=COM:2021:101:FIN (06.01.2021).

Folgheraiter, F. (2000). *L'utente che non c'è. Lavoro di rete e empowerment nei servizi alla persona*. Trento: Erickson.

Groce, N. & Bakhshi, P. (2019). *Illiteracy Among Adults with Disabilities in the Developing World: An Unexplored Area of Concern*. London: Leonard Cheshire Disability and Inclusive Development Centre.

ILO & OECD (2017). *Labour market inclusion of people with disabilities*. https://www.ilo.org/-wcmsp5/groups/public/—dgreports/—inst/documents/publication/wcms_646041.pdf (06.01.2021)

ISTAT (2019). *Conoscere il mondo della disabilità. Persone, relazioni, istituzioni*. Roma https://www.istat.it/it/files/2019/12/Disabilit%C3%A0-1.pdf (06.01.2021)

ISTAT (2021). Audizione dell'Istat presso il Comitato Tecnico Scientifico dell'Osservatorio Nazionale sulla condizione delle persone con disabilità. https://www.istat.it/it/files/2021/03/Istat-Audizione-Osservatorio-Disabilit%C3%A0_24-marzo-2021.pdf (06.01.2021).

Reed, N. S., Meeks, L. M., & Swenor, B. K. (2020). Disability and COVID-19: who counts depends on who is counted. *The Lancet Public Health*, 5(8), e423.

Sen, A. (2005). Human rights and capabilities. *Journal of human development*, 6(2), 151-166.

Taddei A. (2019). La pedagogia speciale tra sguardi filosofici e pratiche metodologiche: prospettive emancipatorie. *Italian Journal Of Special Education For Inclusion*, 7(1): 67-78.

United Nations (2006). *Convention on the Rights of Persons with Disabilities*, NewYork. https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en (06.01.2021).

United Nations (2015). *The 17 Goals*. Department of Economic and Social Affairs Sustainable Development, New York. https://sdgs.un.org/goals (06.01.2021).

Wheaton, F. V., & Crimmins, E. M. (2016). Female disability disadvantage: a global perspective on sex differences in physical function and disability. *Ageing & Society*, 36(6), 1136-1156.

World Medical Association (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. Jama, 310(20), 2191-2194.

World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva.

World Health Organization. (2008). *Training Manual on Disability Statistics*. Geneva. https://unstats.un.org/unsd/censuskb20/Attachments/2008ESCAP_TrainManDisabty-GUID7c07895389164cdab0b0b7609136f117.pdf (06.01.2021).

World Health Organization. (2011). *World Report on Disability*. Geneva. https://www.who.int/disabilities/world_report/2011/report.pdf (06.01.2021).

World Health Organization. (2020). *Disability considerations during the COVID-19 outbreak* (No. WHO/2019-nCoV/Disability/2020.1). World Health Organization.

Wheaton, F. V., & Crimmins, E. M. (2016). Female disability disadvantage: a global perspective on sex differences in physical function and disability. *Ageing & Society*, *36*(6), 1136-1156.