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Improvement of coherence and comparability of data on children with disabilities**Social inclusion: a new survey on children with disabilities and their families****Note by the Italian National Institute of Statistics****Abstract*

As required by Article 31 (Statistics and data collection) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Italian Institute of Statistics (Istat) has progressively diversified data collection to ensure that more persons with disabilities are captured in the statistics, thus facilitating the implementation, and monitoring of the Convention itself. Recently, to get a more exhaustive picture of the social inclusion of children with disabilities, Istat has designed an ad-hoc survey targeting youth under 18 years with disabilities to be rolled out in 2024. The survey also includes a control sample without disabilities which makes it possible to monitor social inclusion from a comparative perspective. The results will also be published on the institutional website "DisabilitàInCifre" that disseminates official disability statistics.

This paper aims to share the main features of the survey: (a) questionnaire designed to collect information not only on the social inclusion of children with disabilities but also on any difficulties families may encounter (i.e. accessing services and reconciling care and work); (b) integration between administrative information (disability certifications) and information collected through disability measurement tools (Global Activity Limitation Indicator-GALI and the UNICEF-WG Child Functioning Module-CFM); (c) use of a new disability register, established by Istat integrating various administrative sources, to build a sample based on the demographic structure of the population with disabilities.

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I. Introduction

1. It is well known that all over the world, too many children are denied their rights and face the future with their needs unaddressed; this prevents them from fulfilling their potential as well as achieving the fullest possible social inclusion. Children with disabilities have to confront additional challenges due to the many barriers (environmental and cultural) they have to overcome in society. Indeed, children with disabilities stumble upon different forms of exclusion that affect them to varying degrees, depending on the type of impairment, environment and culture. Children with disabilities are more likely to experience violence, abuse, exploitation, be marginalized in institutions and have limited access to school, healthcare or participation in social life compared to children without disabilities.
2. The U.N. Convention on the Rights of the Child (UN 1989) and the U.N. Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) set out the fundamental rights that must be recognized and guaranteed to all children without distinction of any kind. Therefore, those U.N. conventions constitute the standards for promoting and protecting the rights of children with and without disabilities. Furthermore, they call upon all States to develop and implement policies and programmes to eliminate barriers that inhibit their full and effective participation in society on an equal basis with others. The 2030 Agenda for Sustainable Development aims to create a “just, equitable, tolerant, open and socially inclusive world in which the needs of the most vulnerable are met”. Doubtlessly, children with disabilities are one of the world’s most vulnerable population groups. Therefore, the commitment to “leave no one behind” calls for a disability-inclusive development. To this end, considering disability as a cross-cutting criterion in collecting data is a must.
3. The International Classification of Functioning, Disability and Health (ICF; WHO 2001) is a guiding framework for disability measurement. The definition reflects the evolution of the concept of disability, where disability is no longer considered as an individual attribute but rather as the negative result of the interaction between an individual (with a given health condition) and the individual’s contextual factors (environmental and personal). The new definition of disability has changed the approach adopted in the design and implementation of social policies and services and, consequently, the contents of the statistical surveys that provide the information needed to plan and evaluate policies.
4. All of the above represents a challenge for governments and producers of official statistics alike. Governments have to take the responsibility to ensure that all children enjoy their social, cultural, economic and political rights without discrimination of any kind by implementing integrated policies based on reliable data. In order to improve the living conditions of children with disabilities and their families, to foster their full participation and fulfil their potential, it is of the utmost importance to gather accurate and up-to-date data, disaggregated not only by the usual socio-demographic variables but also by disability. Otherwise, it would be impossible to monitor progress in the implementation of the UN conventions and towards the SDGs set for children with disabilities. Therefore, national statistics offices have to strive to obtain data that fulfils the information needs of policymakers and other stakeholders. In particular, two kinds of indicators are needed to design, implement and monitor the policies on disability: status indicators (disability identifiers); and outcome indicators (measuring social inclusion: education achievement, social participation etc.)

5. Back in 1999, the Italian National Institute (Istat) developed a statistical information system on disability called "Disability in Figures1" that collects, systematises and disseminates data on disability. Through the website, stakeholders can easily access all official data, regularly updated, from administrative and population surveys. The information system is part of a strategy for producing statistical data on disability that is currently undergoing an extensive renewal process, with the aim of identifying and establishing new data sources suitable for fulfilling the increasing demand. A strong impetus in this direction also comes from Article 31 (Statistics and data collection) of the UNCRPD.
6. Currently, there are gaps in the Italian data collection on child disability, due to difficulties in measuring child disability in population surveys, budget issues and some limitations imposed by the country's strict privacy laws. In particular, the available data, whether from administrative sources or population surveys, does not provide a comprehensive picture of the social inclusion of children with disabilities. To address this issue, Istat has recently designed an ad-hoc survey targeting youth under 18, with and without disability, enrolled in school. This is the first survey in Italy specifically focused on aspects of the social inclusion of children with disabilities and the barriers they face in exercising their rights. Addressing the level of inclusion and related barriers in several areas, the survey intends to bring about a more complete understanding of the life conditions of children with disabilities through indicators that evidence progress in the UNCRPD implementation, whilst also pointing out the persistent disparities in children's circumstances that need to be overcome.
7. This paper aims to share the main features of the survey: (a) questionnaire designed to collect information not only on the social inclusion of children with disabilities but also on any difficulties families may encounter (i.e. accessing services and reconciling care and work); (b) integration between administrative information (disability certifications) and information collected through disability measurement tools (Global Activity Limitation Indicator-GALI and the Washington Group/UNICEF Module on Child Functioning-CFM); (c) use of a new disability register, established by Istat integrating various administrative sources, to build a sample based on the demographic structure of the population with disabilities.

II. Survey on children with disabilities and their families: main features

A. Survey design

8. The need to conduct an ad-hoc survey of children with disabilities arose not only to comply with Article 31 of the UNCRPD and thus to meet the information needs of policy makers, but also because of the ongoing dialogue with other data users. Associations of people with disabilities are also calling for a broader representation of the living conditions, needs and barriers that prevent children with disabilities from exercising their rights on an equal basis with other children. In addition, in carrying out the annual survey "School inclusion of

¹[https://disabilitaincifre.istat.it/dawinciMD.jsp?a1=u2i4W000GaG&a2=__&n=\\$\\$\\$1\\$\\$\\$\\$\\$\\$\\$&o=&p=hm&sp=null&l=1&exp=0](https://disabilitaincifre.istat.it/dawinciMD.jsp?a1=u2i4W000GaG&a2=__&n=$$$1$$$$$$$&o=&p=hm&sp=null&l=1&exp=0)

students with disabilities”², which monitors inclusion and participation in schools of students with disabilities, the families stressed the need to capture the difficulties they faced and the complexity and burden of caring for children with disabilities. In the design phase of the survey, the associations of people with disabilities and some national disability experts were active participants not only as bearers of information needs but also as partners for a successful development of the survey.

9. The survey was planned with the following main objectives: a) measuring the inclusion of children and teenagers with disabilities in various life contexts, b) capturing family care burden, c) using international survey tools to detect childhood disability, d) selecting a sample of students with disabilities that reflects the specific socio-demographic structure of this population, using administrative source data.
10. Furthermore, in compliance with UNCRPD and with the aim of measuring inequality, the survey includes a control sample of children without disabilities. During the survey data analysis, the control sample makes it possible to compare the two sub-populations (children with and without disabilities and their respective families) pinpointing persistent disparities in children’s circumstances, the disservices that affect all families in equal measure, and the difficulties that are specific to families with children with disabilities. Therefore, the survey – to be rolled out in the field this coming April - targets children or teenagers (from 3 to 17 years) enrolled in school who hold disability certification, and a control sample of children or teenagers without a disability certification.
11. The primary giver of the child (with or without disabilities) selected will be the survey respondent. Regarding families, the socio-demographic and economic characteristics will be collected to describe the family context in which the student lives and the impact on the daily management of the work of caring for a child with disabilities. As for students, the survey will collect aspects of school and daily life to measure school and social inclusion; the difficulties in the diagnostic paths to obtain a final diagnosis are also explored, as well as the type of social and health services that families benefit from and any access difficulties.

B. Identification of population with disability

12. Identifying the most appropriate administrative data source for extracting a representative sample of the specific socio-demographic structure of children and teenagers enrolled in schools was a challenge, particularly for those with disabilities. Initially, Istat contacted the Ministry of Education to ascertain whether any of its administrative data sources could be used to build the population sample. However, the country’s strict privacy laws did not allow its use for children and teenagers with disabilities. Since Istat was working on a new administrative data source register, called “Disability Register”, it was decided to post-pone the survey until this Register could be used. The register was established in accordance with Law 18/2009, which ratified the UN Convention on the Rights of People with Disabilities. It has three main purposes: 1) to identify the population with significant health problems; 2) to release statistical information for monitoring the national inclusion policies and the implementation of the rights as stated by the UNCRPD; 3) to build an accurate sampling

² For more information see S. Corradini, L.Martinez “On the road to inclusion: a survey on schools and students with disabilities in Italy”.

base for ad-hoc statistical surveys on disabilities. So far³, the Register has linked two databases produced by the National Institute for Social Security (INPS): Disability Certification Register and Beneficiaries of Disability Pensions Register (INPS). This made it possible to retrieve the children who had received their disability certification before 2010 and had not received further certification. In fact, prior to 2010 the Disability Certification Register archive was only paper-based and its reliability across the national territory uneven. Thanks to the new Disability Register, it was possible to extract an accurate sample with the features required for the survey.

C. Questionnaire design

13. A particularly delicate and demanding phase of the survey planning was the design of the questionnaire, which involved also external experts and representatives of disability associations whose technical competence and experience were crucial.
14. Keeping in mind that the questionnaire design is essential in order to obtain valid and reliable data, the research team drafted the questionnaire structure and the questions in such a way as to reduce respondent burden and, at the same time, to collect a set of accurate information to study social inclusion and participation of the child, as well as the main issues faced by the primary caregiver(s) in the childcare management. The questions were developed ensuring that they had the same meaning for all respondents, were easily understood and could be answered correctly by the respondents, and could be properly administered during the Computer Assisted Telephone Interview (CATI).
15. The questionnaire design consisted of three main steps: development of the questionnaire conceptual scheme, drafting the questions and testing the questionnaire. In order to design a conceptual scheme that accurately portrayed reality, the research team conducted an analysis of both national regulations and literature. The legislation highlighted the child rights and contexts to be detected and analyzed; literature review and consultation with national disability associations made it possible to identify the main dimensions to be measured. Having identified the dimensions and information to be collected, the research team reviewed Istat surveys to select appropriate questions when available. Whenever the dimensions and information had not been previously investigated by Istat, the questionnaires of other countries statistics institutes were reviewed. The questionnaire development also considered the data collection modes (CAWI and CATI).

III. The questionnaire

16. Since the survey sample consists of students with and without certified disability, different pathways are foreseen along the seven thematic areas of the questionnaire. In addition,

³ The full implementation of the “Disability Register” requires the integration of additional administrative archives that contain “events” referable to acts or procedures linked to the presence of individual health problems, such as: flows on work permits, tax and social security contributions relief for people or companies, linked to a disability condition (INPS, Central of active positions; Revenue Agency, Model 730, 770 and UNIQUE Model).

several filters identify relevant questions and appropriate answer categories for the two samples within each area.

17. The first section, Health, aims to measure children's health status and "functioning" - according to the ICF perspective- level of functioning difficulty and use of assistive devices.
18. The second, Diagnostic path, is targeted only to households whose child has a certified disability. The questions ask about type of certification and related health issues, how and when the final diagnosis was obtained, any obstacles encountered during the diagnostic process, and any support received after the disability certificate was issued.
19. The third, Use of Services, aims to capture any difficulty in accessing health and social services, needs and unmet needs in childcare.
20. The fourth, Work flexibility and childcare burdens, evaluates the working conditions of the parents or caregivers, work flexibility and any changes in their work conditions to take care of the child; the difficulties that parents or caregivers encounter in reconciling ordinary activities (carrying out family tasks, employment activities and free time) with caring for their child; and finally, the support received from childcare services or informal networks.
21. The fifth, School inclusion, investigates participation and involvement of children, and their families, in school life; level of satisfaction and adequacy, from the parent's point of view, of all the supports (school staff and equipment/devices/educational aids) offered by the school system to overcome the student's difficulties.
22. The penultimate section, Social participation, investigates the child's participation in social life (hanging out with friends, participating in social activities, playing sports, using technology) and the presence of barriers that hinder participation.
23. The last section collects information about each family member to describe the socio-demographic context in which the child lives (age, educational qualifications, professional status of the family members, and marital status of the parents).
24. The questionnaire was finalized in collaboration with national disability experts and national associations to assess the questionnaire, from the respondent's point of view, and verify whether the complexity of the issues had been captured.

IV. Use of international measures

25. Each country has its own Law(s) and disability certification process with different thresholds to issue certification, therefore some individuals are more easily recognized as persons with disabilities than others in different contexts. Data based on disability certification are only partly comparable and do not cover the entire population of people "at risk" of disability.
26. For the population surveys, international disability measures are available; this represents an important step towards a full comparability of child disability within a country as well as between countries.
27. Therefore, three different international survey tools were introduced in the questionnaire: 1) Minimum European Health Module; 2) UNICEF-WG Child Functioning Module; 3) some

items taken from the “Index for inclusion, developing learning and participation in schools”⁴.

28. The inclusion of the international measures on functioning and disability has two objectives. The first is to analyse the functioning of the population in order not only to detect children with functional limitations but lacking medical certification, but also to compare the level of participation taking into account a standardized scale of measurement. The second, of a methodological nature, is to compare results based on perceived and self-reported measures with the results based on the medical approach used in the certification process.
29. The selected items from “Index for inclusion” measure the level of inclusion in school using the parent's subjective point of view on specific aspects such as the relationship with teachers, curricular and learning support, and the relationship between peers.

A. Minimum European Health Module

30. In the European Statistical System, the Minimum European Health Module (MEHM) is used in European health and social population surveys –under regulations- to measure three different concepts of health: self-perceived health, chronic morbidity and activity limitations. Two questions measure the latter’s degree by asking whether a person is limited in activities people usually do -because of a health problem- on a continuum scale from severely limited to not limited at all, and a second question asks whether the person has been limited for at least the past six months. These two questions make up the GALI (Global Activity Limitation Indicator) that is meant as a global self-reported measure of participation restriction in line with the ICF. GALI is used to assess disability and as a breakdown variable to present the indicators by disability status. Since a GALI-like variable for children is available, it has been included in the questionnaire together with the other components of the MEHM.

B. UNICEF-WG Child Functioning Module

31. UNICEF and WG developed an ad-hoc survey tool to measure disabilities in children named Child Functioning Module (CFM)⁵. This tool has two versions: one for children aged 2-4 years old and one for children aged 5-17 years old. Both are designed for administration to mothers (or primary caregivers). The CFM assesses difficulties in the following functional domains: vision, hearing, mobility, communication/comprehension, behaviour, and learning (all ages); dexterity and playing (2-4 years); and self-care, remembering, focusing attention, coping with change, relationships and emotions (5-17 years). The purpose is to identify children who are more at risk of experiencing limited participation in an unaccommodating environment. As disability is not inherently a dichotomous yes/no phenomenon, difficulty in functioning is measured against a continuum scale. The set of questions is intended for use in national and international household surveys.
32. Istat has actively collaborated in the development of the CFM, also testing a draft version; nevertheless, this survey represents the first opportunity to include the module that will be

⁴ T. Booth and M. Ainscow, Index for inclusion: developing learning and participation in schools, 2002 CSIE.

⁵ <https://data.unicef.org/topic/child-disability/data-collection-tools/module-on-child-functioning/>

administered to the primary caregivers for whole students sample in order to analyse level of participation, taking into account the type of functioning limitations and their severity.

C. Index for inclusion, developing learning and participation in schools

33. The Index is a resource to support the development of inclusive schools. Since it is a self-evaluation and self-improvement proposal for schools of all levels, it gives schools the capacity, through a detailed examination of barriers to learning and participation, to ensure that every person within it – students but also teachers – is always given the opportunity to participate fully and equally realize their potential. Inclusion and exclusion are measured based on three interconnected dimensions of school improvement: creating inclusive cultures, producing inclusive policies and evolving inclusive practices. The index was introduced in the questionnaire to correctly describe some aspects of school inclusion such as information sharing, collaboration with parents, recognition of diversity as an opportunity, tackling discrimination.

V. Survey Implementation

34. The survey launch is foreseen in April. For the population groups under investigation, two different samples were extracted to reproduce the structure - by age, sex and territory - of students with disabilities (listed in the Disability Register as having a certification issued by the medical-legal commissions) and without disabilities (listed in the Municipal Population Register), respectively. This allowed, for the first time, to keep under control the different age and sex structures of the two populations. Each household has been extracted only once, in drawing the student samples, to reduce respondent burden. The overall final sample consists of 40 thousand students: 20 thousand children with disabilities and 20 thousand without disabilities.
35. Regarding the data collection mode, the questionnaire can be administered using two different techniques: 1) Computer Assisted Web Interview (CAWI) and 2) Computer Assisted Telephone Interview (CATI). These interview techniques have been selected based on aspects such as scope, contents, and number of survey variables, as well as questions' sensitivity and possible information retrieval problems. Computer Assisted Personal Interviewing (CAPI) was ruled out because it is inadequate when interviewing respondents who are dispersed across the territory, as in the case of children with disabilities, and would only be feasible by deploying an excessive number of resources with a consequent increase in survey costs. The reason for the technique alternatives is that the CAWI technique alone can lead to a selection of respondents determined by the different aptitudes in using technology and different availability of adequate devices; these factors often correlate with specific sociodemographic characteristics, such as educational qualification or age. This can result in a "non-random" selection of respondents, producing distortions in data collection; hence, offering CAWI and CATI techniques is necessary.
36. For each of the two sub-populations under investigation (children with disabilities and without disabilities), two different samples have been selected. One representative of the population having a telephone number listed in the Register and to whom the questionnaire

is administered by CATI; the second one representative of the population that does not have a telephone number and to whom the questionnaire is administered by CAWI. However, households selected for CAWI could request a telephone interview, thus switching to CATI technique. This makes it possible to include respondents who cannot proceed with the self-compilation due to inability or lack of technology.

VI. Conclusion

37. This paper's main purpose is to share the Italian experience in planning the "Survey on children with disabilities and their families", the first survey specifically designed for children and teenagers with disabilities - with a control sample without disabilities. When rolled out in the field (April 2024), it will provide a wider indicator on social inclusion of children with disabilities and barriers that hinder their inclusion with respect to children without disabilities. Furthermore, the survey addresses the family care burden of children with disabilities, from difficulties in obtaining the child's final diagnosis, accessing health and social services and receiving ad-hoc interventions, to difficulties in managing childcare with other family, personal and work-related duties.
38. The survey and questionnaire design required a lot of effort, on the one hand, to ensure the accuracy and quality of the data and, on the other hand, to ensure the protection of the privacy of the investigated population.
39. With the UNCRPD as background framework, the literature and survey tools review as well as the collaboration with national disability associations were crucial in identifying the main area, and within it the specific aspects to be investigated. Disability in children is captured using two international survey tools (GALI and CFM) that deliver internationally comparable data. Using both tools makes it possible to compare the two sub-populations detected by these different measures. In addition, these sub-populations, captured using the ICF biopsychosocial approach, can be compared against the sub-group population having a disability certificate, identified by the medical approach.
40. Finally, an integration process of various administrative data sources, resulting in the "Disability Register", was essential to build a sample that reflects the specific demographic structure of children with disabilities. The Register as a starting list makes it possible to obtain more accurate estimates and to evaluate the presence of any distortions in the assessments coming from other population surveys.
41. Data resulting from the survey will be not only disaggregated by status of disability, as requested by the UNCRPD and SDGs for their monitoring, but also by type of functioning limitation providing reliable, valid and comparable data on children with disabilities.

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