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Research paper

Navigating the landscape of child disability measurement: A review of available data collection instruments



Comprendre la mesure du handicap de l'enfant : examen des instruments de collecte de données

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ARTICLE INFO

Article history:

Received 4 May 2015

Accepted 5 August 2015

Keywords:

Child disability

Survey

Census

Prevalence

Disability

International

ABSTRACT

The United Nations Convention on the Rights of Persons with Disabilities adopted in 2006 holds States responsible to "...collect appropriate information, including statistical and research data, to enable them to formulate and implement policies..." This recognition has led to an increasing number of countries gathering data on disability at the population level; however, there are currently no gold standards for its measurement and different data collection tools have been used throughout the years to fulfil data needs. Understanding how these differences have influenced the measurement of disability globally is crucial to developing reliable and comparable measures. The purpose of this paper is to describe the varying scope and content of data collection instruments on child disability and to provide a historical snapshot of the rates of reported disability among children. A total of 716 data sources were identified, corresponding to 198 countries covering more than 95% of the world's children. The findings reveal a lack of consistent definitions and measures of disability, which contribute to major challenges in producing reliable and comparable statistics.

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R É S U M É

Mots clés :
 Enfants handicapés
 Enquête
 Recensement
 Prévalence
 Handicap
 International

La Convention des Nations Unies sur les droits des personnes handicapées adoptée en 2006 impose aux États de « recueillir des informations appropriées, y compris des données statistiques et résultats de recherches, qui leur permettent de formuler et d'appliquer des politiques ». Cette mesure a conduit un nombre croissant de pays à se lancer dans la collecte de données sur les personnes handicapées ; cependant, il n'y a actuellement pas de standards internationaux pour guider la collecte, si bien que différents outils ont été utilisés au fil des ans pour satisfaire ce besoin de données. Comprendre de manière générale comment ces différents outils ont influencé la mesure du handicap est essentiel afin d'aller vers l'élaboration de mesures fiables et comparables. L'objectif de cet article est de décrire la variabilité des différents instruments de collecte de données sur le handicap chez l'enfant, tant dans leur forme que dans leur contenu, et de fournir un point de vue historique sur les taux de prévalence estimés. Sept cent seize sources de données ont été identifiées, issues de 198 pays et concernant plus de 95 % des enfants à l'échelle mondiale. Il en ressort un manque de définitions et de mesures cohérentes du handicap, qui mettent en évidence les défis majeurs qui restent à relever dans la production de statistiques fiables et comparables.

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1. Introduction

Reliable data are central to gaining the confidence of decision makers and the greater community when advocating for legislation, policies, funding, programming and the inclusion of disability on national and international political agendas (Albert, Dube & Riis-Hansen, 2005; Eide & Loeb, 2005; Fujiura, Park & Rutkowski-Kmitta, 2005). Furthermore, data allows policymakers, programme staff and researchers to monitor the level of disability within a population and to understand trends in disability prevalence; impacts of improvements in survival and exposures to nutritional deficiencies, environmental toxins, serious diseases and trauma; and interventions designed to improve child health and development (Durkin, 2001). Having statistics that are comparable can also highlight international and intra-national inequities between different populations of children with disabilities, for example by ethnicity, sex, age, region, or type of impairment (Robson & Evans, 2003).

With the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 during the sixty-first session of the United Nations General Assembly¹ (United Nations Enable, 2014), the international community acknowledged both the need and importance of reliable, valid and comparable data on persons with disabilities. Although efforts to collect disability statistics are not new, Article 31 of the Convention holds States Parties responsible, for the first time, to "...collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (United Nations General Assembly, 2006). This recognition has led to increased attention, interest, commitment, and resources for collecting data on disability (Schneider, 2009; Trani & Bakhshi, 2008).

Despite this, there have been major challenges in producing reliable and comparable disability statistics due in large part to a lack of consistent definitions and indicators of disability, combined with differences in methodologies used to gather data and quality of study designs. In 2002, the UN General

¹ There were 159 signatories to the Convention as of 1 December 2014. Signatories include countries or regional integration organizations that have either ratified, acceded or signed the Convention and its Optional Protocol.

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