



Salud Pública de México

ISSN: 0036-3634

spm@insp.mx

Instituto Nacional de Salud Pública
México

de Castro, Filipa; Hubert, Celia; Strand, Erika; Prado, Eva; Braverman, Ariela
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Sustainable Development Goals
Salud Pública de México, vol. 59, núm. 4, julio-agosto, 2017, pp. 354-360
Instituto Nacional de Salud Pública
Cuernavaca, México

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Severe functional difficulties and disabilities in children and adolescents and the Sustainable Development Goals

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De Castro F, Hubert C, Strand E, Prado E, Braverman A.
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<https://doi.org/10.21149/8487>

Abstract

Objective. To report prevalence of severe child functional difficulties and disability (CFD) in a nationally representative sample of 2 to 17 year-old children in Mexico and describe the inequities faced by children with CFD in relation to a set of Sustainable Development Goals (SDG)-related outcomes. **Materials and methods.** Using data from the National Survey of Children and Women (ENIM 2015) we estimate prevalence with 95% confidence intervals for the selected indicators. We use chi-square test and confidence intervals inspection to report significant differences between children with and without CFD. **Results.** 8% of children present at least one CFD. CFD is associated with higher prevalence of underweight and child labor and lower prevalence of adequate early child development. **Conclusion.** Children with CFD present worst outcomes and require targeted efforts to ensure they meet health and wellbeing targets in the frame of the SDGs.

Keywords: disability; health inequalities; child advocacy; United Nations; child development

De Castro F, Hubert C, Strand E, Prado E, Braverman A.
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en niños y adolescentes frente a los Objetivos
de Desarrollo Sostenible.
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<https://doi.org/10.21149/8487>

Resumen

Objetivo. Reportar la prevalencia de problemas severos de funcionamiento y discapacidad (CFD) en una muestra representativa de niños y niñas de 2 a 17 años en México y describir las inequidades enfrentadas por los niños y niñas con CFD respecto a un conjunto de indicadores relacionados con los objetivos de desarrollo sustentable (ODS). **Material y métodos.** A partir de datos de la Encuesta Nacional de Niñas, Niños y Mujeres en México (ENIM 2015), se estiman prevalencias e intervalos de confianza al 95% para indicadores seleccionados. Se usa prueba de ji cuadrada e intervalos de confianza para reportar diferencias significativas entre niños/as con y sin CFD. **Resultados.** 8% de los niños presentan al menos un CFD. Los CFD se asocian con mayor prevalencia de bajo-peso y trabajo infantil, y con menor prevalencia de desarrollo infantil temprano adecuado. **Conclusión.** Los niños con CFD presentan resultados desventajosos, y requieren esfuerzos enfocados que garanticen el alcance de las metas de salud y bienestar en el contexto de los ODS.

Palabras clave: discapacidad; desigualdad en salud; defensa del niño; Naciones Unidas; desarrollo infantil

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Received on: January 10, 2017 • **Accepted on:** May 25, 2017

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The Mexican National Survey of Girls, Boys, and Women (ENIM 2015) was implemented to generate information on the current situation of children and women in Mexico from a large number of indicators, some of which are presented for the first time in the country.

While Mexico has a robust system of statistics based on surveys and registers, the need for specific information with an emphasis on children was central to the decision to carry out the ENIM 2015, as a standardized survey based on the 5th round of the Unicef supported Multiple Indicator Cluster Sample (MICS) program. Its standardized nature allows comparisons between countries in many global and regional indicators, which was an additional benefit for Mexico.

In September 2015 the United Nations General Assembly established the Sustainable Development Goals (SDG). These include 17 goals, 169 targets, and 230 indicators that will provide guidance for countries to globally monitor their progress. The information gathered by the ENIM 2015 allowed for the generation of baseline information aligned with 15 SDG indicators,* which will facilitate monitoring and evaluation of Mexico's progress towards those goals:¹

- SDG 2: End hunger, achieve food security and improved nutrition, and promote sustainable agriculture.
- SDG 3: Ensure healthy lives and promote well-being for all at all ages.
- SDG 4: Ensure inclusive and equitable education and promote lifelong learning opportunities for all.
- SDG 6: Ensure availability and sustainable management of water and sanitation for all.
- SDG 8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all.
- SDG 16: Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels.

The pledge that no one will be left behind framed the general commitment made by Heads of State and Government when subscribing the new global SDGs. In that sense, the 17 Goals and targets shall be met for all nations and peoples and for all segments of society, reaching the furthest behind first. To meet this pledge,

* Since not all the indicators are strictly following the SDG definitions we will refer to the indicators as the SDG-related indicators throughout this paper

the SDG's monitoring and evaluation framework aims to report on progress for all using rigorous, high quality data and evidence, disaggregated by income, sex, age, race, ethnicity, migration status, disability and geographic location, as well as other characteristics particularly relevant for each country.

Evidence from the Global Burden of Disease study revealed that 95 million children (5.1%) 0 to 14 years live with disabilities, of which 13 million (0.7%) present severe disabilities.² Previous evidence also shows that children from poor households and those in ethnic minority groups are at higher risk of disability than other children.³ Moreover, children living with disabilities face several other inequities such as limited access to education and health services.^{4,5}

Information about the prevalence of CFD and the vulnerabilities faced by these children in Mexico is scarce. Updated population evidence is urgent to orient advocacy efforts and decision making that can positively affect the health and wellbeing of those children and adolescents facing higher risks of being left behind in the progress towards the new SD goals. The aims of this paper are:

1. To report the prevalence of severe child functional difficulties and disability in a nationally representative sample of 2 to 17 year-old children in Mexico.
2. To describe national SDG outcomes for each indicator and to contrast them with those of children with severe functional difficulties and disability.
3. To assess differences in SDG outcomes according to functional difficulties and disability.
4. To point out, based on the data analysis, the need for special policies and programs to address the needs and fulfill the rights of children with functional difficulties and disabilities.

Materials and methods

Sample

We used the Washington group-Unicef module on functional difficulties and disability for children aged 2 to 4 and for children and teenagers aged 5 to 17 of the ENIM 2015. In line with the bio-psycho-social model of disability, this module focuses on the presence and extent of functional difficulties rather than on body function and structure or conditions, i.e. causes of those difficulties. These functional difficulties may place children at risk of experiencing limited participation in an unaccommodating environment.

As detailed elsewhere⁶ the ENIM, the Mexican implementation of Unicef's MICS, is a probabilistic,

multi-stage, cluster, household survey. The Ethics Committee of the National Institute of Public Health of Mexico approved the survey research protocol, letters of consent and instruments. We obtained letters of consent from all participants.

The sample used in this analysis consists of 16 617 children and adolescents whose mothers answered the WG/Unicef child disability module (5 010 children aged 2-4 and 11 607 children and adolescents aged 5 to 17).

Instruments

As De Castro and colleagues reported,⁶ the ENIM consisted of four questionnaires: a Questionnaire for Children under Five, a Questionnaire for Children and Adolescents (5 to 17 years old), a Questionnaire for Individual Women (15-49 years old), and a Household Questionnaire. We used data from all of these instruments but the Women's questionnaire to calculate the SDG-related indicators and to classify respondents as having at least one CFD or not having any.

As a first step in the analysis, we computed the SDG-related indicators using the adequate information from the corresponding questionnaire. We used information from the Children under Five questionnaire for the following five SDG-related indicators: Stunting, Underweight, Birth Registration, Full Immunization Coverage, and Early Childhood Development index. Full Immunization Coverage indicator is reported for children 24 to 35 months of age, and the Early Childhood Development index indicator is reported for children between 36 and 59 months-old. The remaining indicators are calculated for children between zero and 59 months.

We used information from the household questionnaire for child labor, violent discipline, use of improved drinking water sources, use of improved sanitation, and place for handwashing. These indicators help characterize the households to which the children in the sample belong. In this case, the SDG-related indicators are applicable to the whole sample of children and adolescents aged 2 to 17 years.

A dichotomous variable was generated to identify children with severe functional difficulties based on the answers provided by the mother/caretaker to the WG/UNICEF child disability module. This variable was generated separately for children aged 2 to 4 and for children and teenagers 5 to 17 according to the domains that apply to each age group.⁷

For children two to five years old, the variable identifies if the child has CFD in any of the following 9 domains: seeing, hearing, walking, understanding, being understood, learning things, learning names, playing,

and controlling behavior. The level of functional difficulties or disability is estimated by asking the mother if the child has *no difficulty*, *some or a lot of difficulty*, or *cannot do it at all*, and for controlling behavior by comparing how often the child misbehaved compared to other children (*does not do it*, *the same or less*, *more*, *much more*). A child was classified as having at least one CFD when at least one question was responded as a *lot of difficult* or *cannot do it at all* (or, *much more* for controlling behavior).

For children and adolescents aged 5 to 17, the variable identifies if the child has CFD in any of the following 14 domains: seeing, hearing, walking, feeding or dressing, being understood inside the household, being understood outside the household, learning, remembering, anxiety, depression, controlling behavior, focusing, accepting change, and making friends. The level of functional difficulties or disability is estimated by asking if the child has *no difficulty*, *some or a lot of difficulty*, or *cannot do it at all*; for anxiety and depression by how often the difficulty occurs (*daily*, *weekly*, *monthly*, *a few times a year* or *never*); and, for controlling behavior by how difficult it is for him/her to control his/her behavior compared to other children of the same age (*none*, *the same or less*, *more*, *much more*). A child or teenager was classified as having at least one CFD when the answer to at least one question was as a *lot of difficult* or *cannot do it at all* (*daily* anxiety or depression; or, *much more* for controlling behavior).

Data analysis

First, we calculated prevalence with 95% confidence intervals for the selected SDG indicators, for children with at least one CFD and compared these results with those obtained for children at national level. Then, we also estimated prevalence with 95% confidence intervals for the selected SDG indicators, for children with and without CFD. Chi squared tests and comparison of 95% CI were used to report the statistical significance. For all analyses, we used Stata 14.0 and its *svy* commands for analyzing complex survey design data.

Results

Table I presents the SDG-related indicators obtained at the national level compared to those calculated for children with functional difficulties. Children with functional difficulties present a considerably higher prevalence of underweight (10.7%) than children at national level (3.9%). Likewise, about 39% of children with functional difficulties have an adequate early child development compared to 82.2% of children at national level.

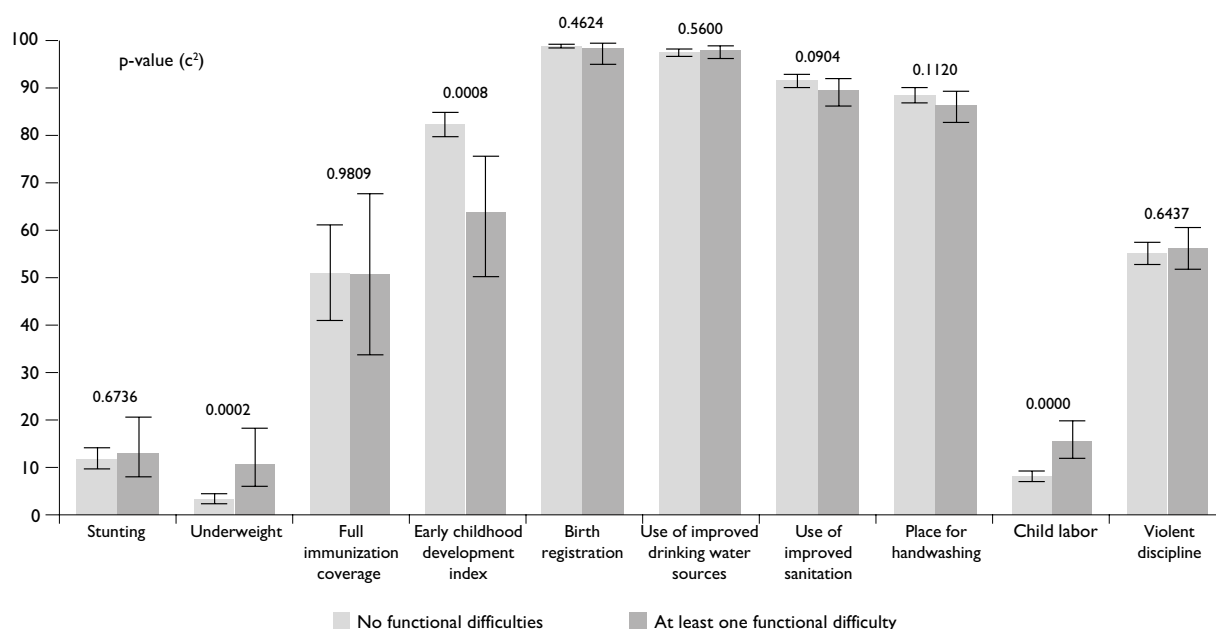
Table I
THE SUSTAINABLE DEVELOPMENT GOALS RELATED INDICATORS AT THE NATIONAL LEVEL AND FOR CHILDREN WITH AT LEAST ONE SEVERE FUNCTIONAL DIFFICULTY. MEXICO, ENIM 2015

Goal	SDG	ENIM Indicator		Goal	National	With at least one severe functional difficulty
SDG 2	2.2.1	2.2a	Stunting	End by 2030	12.4	13.0
	2.2.2	2.1a	Underweight	End by 2030	3.9	10.7
SDG 3	3.8	3.8	Full immunization coverage	100% in 2030	42.8	50.9
SDG 4	4.2	6.8	Early childhood development index	(a)	82.2	38.8
SDG6	6.1.1	4.1	Use of improved drinking water sources	100% in 2030	98.1	98.1
	6.2.1a	4.3	Use of improved sanitation	100% in 2030	93.4	89.6
	6.2.1b	4.5	Place for handwashing	100% in 2030	90.3	86.5
SDG 8	8.7	8.2	Child labor	(a)	12.4	15.5
SDG 16	16.2	8.3	Violent discipline	(a)	63.1	56.3
	16.9	8.1	Birth registration	(a)	95	98.5

(a) To be determined

ENIM: Mexican National Survey of Girls, Boys, and Women

SDG: Sustainable Development Goals



SDG: Sustainable Development Goals

FIGURE 1. SDG-RELATED INDICATORS FOR CHILDREN AGED 2 TO 17 WITH AND WITHOUT SEVERE FUNCTIONAL DIFFICULTIES, PREVALENCE, CI95%, AND P-VALUES FOR CHI-SQUARED TEST

Figure 1 illustrates the national prevalence of the SDG-related indicators and the prevalence for children with and without severe functional difficulties. There are no significant differences in the observed prevalence for stunting, full vaccination coverage, birth registration, violent discipline and all household indicators (use of improved drinking water sources, use of improved sanitation, and place for handwashing).

In contrast, there are significant differences regarding Underweight, Early Childhood Development and Child Labor indicators. Prevalence of underweight is three times higher among children with functional difficulties compared to children without functional difficulties (10.7 *vs.* 3.2%). Likewise, children with functional difficulties are less likely to be developmentally on track compared to children with no functional difficulties (82.6 *vs.* 63.9%), and almost two times more likely to be involved in child labor than their peers with no functional difficulties (8.0 *vs.* 15.5%).

Discussion

Recently, functional difficulties and disabilities have received increased recognition as important public health problems and barriers to access fundamental rights. The 2030 United Nations Sustainable Development Goals mandate of leaving no one behind fully recognizes the importance of addressing the needs of people with disability. Identifying inequities that specifically affect children with disabilities, within the SDG framework, provides useful information for designing and monitoring the implementation of targeted interventions that guarantee their full social participation.

This paper reports the inequities experienced by the population between 2 and 17 years of age with functional difficulties and disability in Mexico, for 10 SDG indicators that will measure progress towards the 2030 Agenda. Ensuring the translation of this evidence into action, requires the identification of those children and adolescents who face the highest risk of falling behind the country's progress towards these Goals.

The SDGs are more ambitious than the MDGs (Millennium Development Goals), since they aim to eliminate rather than reduce extreme poverty and include more demanding targets on issues such as health, education, access to clean water and gender equality. In addition to addressing the unfinished agenda of the MDGs, the SDGs aim to address issues previously not included such as: protecting children from violence, exploitation and abuse; ensuring optimal early childhood development; reducing inequality within and among countries; promoting sustainable and inclusive economic growth, among others. In addition its clear

mandate of leaving no one behind poses a great importance on disaggregation.

With regards to children, the 2030 Agenda explicitly addresses the importance of investing in children and their role as agents of change. Although all of the 17 goals and 169 targets of the agenda touch in one way or another the lives of children, specific goals and targets in relation to poverty; hunger and nutrition; health; education; gender equality; water and sanitation; economic growth; and peaceful and inclusive societies, make explicit references to children and youth, both boys and girls.⁸

An equity approach or lens must be applied when analyzing the data that will allow countries to measure progress towards SDG attainment. In that sense, the inequities that children and adolescents with CFD face, reported in this paper, show a clear picture of those areas in which further and concrete action will be needed from all actors committed with the development goals.

The data reported and analyzed in this paper points out the need for special policies and programs not only to address the needs, but also to make sure the rights of almost 4 million children in Mexico living with at least one CFD (8.4%) are guaranteed. Concrete actions are required to improve indicators related to stunting, underweight, early childhood development, and child labor.

In Mexico, stunting and underweight are more prevalent among the most disadvantaged population.⁹ Our results show that children with CFD also have higher prevalence of stunting and underweight compared with those with no CFD functional difficulties. Internationally, there is a growing interest in the links between nutrition and disability^{10,11} as countries with high levels of malnutrition and nutrient deficiency also often report higher rates of disability and developmental delay.¹² While results do not allow to establish a causality between the two, it is likely that an overlap exists, and that malnutrition can contribute to a variety of different disabilities and that, in turn, disability and functional difficulties can contribute to malnutrition.¹⁰ For instance, malnutrition can cause disability from pregnancy onwards, through maternal malnutrition both during the prenatal¹³ and postnatal period.¹⁴ Additionally, macro and micro nutrients deficiency during infancy and childhood have also been linked to higher disability risk.¹⁴ For example, globally it is estimated that each year between 250 000 and 500 000 children become blind as a result of vitamin A deficiency.¹⁵ Vitamin B deficiency in early childhood is associated with several neuropathic disorders, Iodine deficiency affects early cognitive development sometimes irreversibly¹⁵ and Iron deficiency is associated with cognitive, learning and behavioral impairment in children.¹⁶ On the other hand, children with disabilities may also be at higher risk of

malnutrition, due to specific oral-motor and swallowing problems,¹⁷ malabsorption problems,¹⁸ general feeding problems,¹⁹ as well cultural and attitudinal aspects.²⁰

The results show that children with CFD present lower prevalence of on-track development as measured by the Early Child Development Index (ECDI). This association is not surprising given that the ECDI identifies children with any developmental problem, which could result from severe functional difficulties or otherwise non-severe difficulties that left undiagnosed and untreated could result in severe disability.³ Disabled children are not only more vulnerable to risks, such as poverty, malnutrition, stigma and violence that could affect their development, they also experiment less access to early childhood programs and other services targeted at improving child development.²¹⁻²³

As evidenced by the results for child labor prevalence, Mexican children with CFD are more likely to engage in economic activities. Child labor, which is globally recognized as a violation of children's rights, not only negatively affects health and wellbeing it also restrains educational access and further human capital outcomes.²⁴ This result might also reflect the social inequalities faced by families of children with disability. The evidence shows that poor families with disabled members spend a greater proportion of their income on healthcare compared to non-poor families with disabled members, in consequence, the direct and indirect costs associated with child disability are particularly high for poorer families.^{25,26}

Over the last decade, the rights and needs of persons with disabilities have received renewed consideration under the global agenda on population health and development, with the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD),* and a new bio-psycho-social approach to understand disability, functioning and participation.²⁷ Under this paradigm shift, disability is conceptualized as the result from the interaction between a person's difficulties and obstacles in the environment. These contextual barriers include legal, structural and physical barriers as well as prevailing attitudes that can hinder participation in society. The availability of appropriate information, including statistical and research data that enable policy formulation and implementation related to disability, is paramount, and thus, the agenda for the new SDGs requires the identification of the population experiencing functional difficulties and disability through censuses and surveys.

* <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

In 2012 the WHO in collaboration with UNICEF, launched a series of recommendations related to disability, highlighting the importance of providing opportunities from early age to ensure that children with disabilities can reach their development potential and reach full participation in society.¹⁴ The report underscores the urgent need to strengthen and scale up early childhood development initiatives for young children with disabilities and their families that help mitigate the negative impact of disability on children's life. This implies that policies should ensure that children with disabilities have full access to mainstream policies, systems and services, in addition to programs specifically targeted at disabled population and their families.

In conclusion, this paper shows that children with functioning difficulties and disability in Mexico experience significant worst results in terms of nutrition, early childhood development and child labor. This evidence, which previously was not available for this group of the population, is of particular concern for the newly created Integral System for Children and Adolescent Protection (SIPINNA), to ensure that children with disabilities can exercise their human rights, increase their participation within society and achieve the best possible health and wellbeing. In particular, efforts should be made to ensure political and resource commitment to tackling nutrition, early child development and child labor as issues closely related to disability in children and adolescents. Close monitoring of their access to health-care services, education, and poverty level is needed along further research to estimate the magnitude and factors associated with these restrictions and generate recommendations of policies oriented at removing contextual barriers of all sorts.

Declaration of conflict of interests. The authors declare that they have no conflict of interests.

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