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Inclusion of persons with disabilities in emergencies and disasters, an example of its implementation in Mexican Social Security Institute

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Abstract:

Introduction:
Emergencies and disasters can increase the vulnerability of people with disabilities (PWD). Inclusion in preparedness, response and reconstruction activities allows PWD to be more than just beneficiaries. In this article we show the implementation of the methodology developed by PAHO for the inclusion of PWD in the disaster risk reduction in hospitals.

Material and Methods:
Disability Inclusion in Hospital Disaster Risk Management Index was applied in the Physical and Rehabilitation Medical Unit "Villalongin". This is a monothematic facility, 90% of their patients are people with temporal or permanent disability, and it has 50 beds for patients who need rehabilitation and their principal diagnosis are medullar lesions

Results:
In the first evaluation, the levels of inclusiveness in hospital disaster risk management, by evaluation component, were 18.86%, which means non-inclusive. Hospital staff developed an action plan and implemented actions and invested to increase their level of inclusiveness, with a total inversion of $2860 dollars. In their second assessment they achieved a level of inclusion of 86.12% which means inclusive.

Conclusions
People with disabilities are frequently at risk or affected disproportionately in di-

KEYWORDS

Disability.
Inclusion.
Disaster.
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saster situations, emergencies and conflicts due to various factors. The implementation of INGRID-H will not only contribute to the fulfillment of the rights of PWD, but will also contribute to the efforts to have a safer, more inclusive and resilient health sector.

PALABRAS CLAVE

Discapacidad.
Inclusión.
Desastre.
Reducción de riesgos.
Hospital seguro.

Inclusión de personas con discapacidad en emergencias y desastres, un ejemplo de su implementación en el Instituto Mexicano del Seguro Social

Introducción:
Las emergencias y los desastres pueden aumentar la vulnerabilidad de las personas con discapacidad (PWD). La inclusión en las actividades de preparación, respuesta y reconstrucción permite que las personas con discapacidad sean más que simples beneficiarios. En este artículo mostramos la implementación de la metodología desarrollada por la OPS para la inclusión de las PCD en la reducción del riesgo de desastres en los hospitales.

Material y métodos:
Se aplicó el Índice de Inclusión de la Discapacidad en la Gestión del Riesgo Hospitalario de Desastres en la Unidad Médica Física y Rehabilitación "Villalongin". Se trata de una instalación monotemática, el 90% de sus pacientes son personas con discapacidad temporal o permanente, y cuenta con 50 camas para pacientes que necesitan rehabilitación y su principal diagnóstico son las lesiones medulares.

Resultados:
En la primera evaluación, los niveles de inclusión en la gestión del riesgo de desastres hospitalarios, por componente de evaluación, fueron de 18,86%, lo que significa no inclusivo. El personal del hospital desarrolló un plan de acción e implementó acciones e invirtió para aumentar su nivel de inclusión, con una inversión total de 2860 dólares. En su segunda evaluación lograron un nivel de inclusión del 86,12%, lo que significa inclusivo.

Conclusiones:
Las personas con discapacidad con frecuencia corren riesgo o se ven afectadas de manera desproporcionada en situaciones de desastre, emergencias y conflictos debido a diversos factores. La implementación de INGRID-H no solo contribuirá al cumplimiento de los derechos de las personas con discapacidad, sino que también contribuirá a los esfuerzos por tener un sector de salud más seguro, inclusivo y resiliente.

Introduction

Since 2006, the United Nations Convention on the Rights of Persons with Disabilities strengthens participation and social inclusion, stressing the importance of autonomy and the freedom of disabled people to make their own choices. Absence of awareness or availability, high cost, and apathy are among the key reasons for confining many individuals into their homes to live a dependent, excluded life, locked in poverty and stigma[1]. In this case, emergencies can increase the vulnerability of people with disabilities (PWD), they could be less capable of escape from hazards, may lose essential medications or assistive devices and mobility aids, or may be left behind when a community is forced to evacuate. PWD may also have greater difficulty accessing basic needs, including food, water, shelter and health-care services; following the earthquake and tsunami in Japan in 2011, statistics showed that the fatality rate for PWD was 2.06%, versus 1.03% for the general population[2,3].

Inclusion in preparedness, response and reconstruction activities allow PWD to be more than just beneficiaries, but also participate in the humanitarian response. They should participate in the design, implementation, monitoring and evaluation of assistance programs.

Increasing participation of PWD is a task that Mexican Social Security Institute (IMSS) has started to apply in its facilities through the methodology of Pan American Health Organization/World Health Organization (PAHO/OMS) for the inclusion and participation of PWD in emergencies and disasters titled Disability Inclusion in Hospital Disaster Risk Management named INGRID-H (Spanish acronym)[4].

Disasters and disability

In the last decades, disability has had a visible role in the study of disasters; possibly caused by the promotion of a disability perspective based on human rights and demographics and epidemiological factors, like aging and non-communicable diseases.

Different documents support the inclusion of PWD and their human rights and guarantee their fundamental liberties like the Convention on the Rights of Persons with Disabilities signed in 2007. However, a relevant issue was the promotion of actions for the inclusion of PWD in disasters; the Convention in its Article 11 on Situations of risk and humanitarian emergencies, pays particular attention to the obligation of States parties to undertake "*all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters*", and the Sendai Framework for Disaster Risk Reduction 2015-2030 declares urgent and essential disaster risk prediction, plan measuring, and risk reduction in order to protect people, emphasizing that risk reduction practices should reflect a broader preventive approach that considers hazards from multiple perspectives, such as multisectorality, inclusiveness, and accessibility[5, 6].

The impact of disasters is greater in the American hemisphere, the most common events were hydrological and meteorological, additionally we can found seismic activity, landslides and events such as fires and social disturbances, all of them have major effects on populations, infrastructure, and elements like health services, which are essential to provide care during and after emergencies and disasters; In 2018 in Mexico, the impact of disasters left 501 deaths and 802,560 people affected[7], but in all the different data sources there is no information about how many of these people are PWD, this information is necessary if we know they have higher morbidity and mortality than the general population[8].

Across the world PWD are more vulnerable to disasters and this condition are related to the exclusion that they face in their communities and by their governments, because programs or public policies on disaster risk management are not inclusive; in many occasions disability is not understand or is confused, and consider a medical concept or related to charity and compassion. Even those who are in direct contact with PWD (volunteers and family members) are more exposed to treating them as disabled, unconsciously creating an environment of discrimination and isolation. In Mexico, disability prevalence in 2014 was 6%, approximately 7.1 million of habitants, difficulties to walk and visual impairment are the most reported among PWD; the main triggers of disability in the country were diseases (41.3%) and advanced age (33.1%)[9,10].

Disability inclusion in disaster risk management in hospitals

People's vulnerability to the impacts of natural hazards and climate change is determined by social, economic, political, and environmental factors. Disaster risk management aims to address vulnerability in order to reduce risk; therefore it needs to consider the full range of vulnerability drivers, including those that affect persons with disabilities. Their basic and specific needs are frequently ignored or overlooked and at the moment of an emergency, the stress and confusion may reduce the capacity of stakeholders and caregivers to provide help and support for PWD.

As an example, not identifying PWD before, during and after and emergency or the lack of disaggregated data and systematic identification, may result in the "*invisibility*" of PWD and the assessment of their needs, including those carried out during the recovery phase and especially in essential areas like health[11].

In Mexico since 2015, National Coordination of Civil Protection published a Mexican Norm to create a culture about the inclusion in disaster prevention[12], but in the case of facilities there have been the commitment to include this term in the context of safe hospital. Safe Hospital Program in our country has succeeded reducing the vulnerability in hospitals, allowing health facilities whose services, in the immediate wake of an emergency or disaster, remain accessible and functional at their maximum installed capacity; this means that health workers should be prepared to respond to all types of hazards, on the "leaving no one behind" principle. But we had a gap, in this case was the inclusion[13].

In supporting the efforts of the countries, PAHO/OMS developed a methodology titled Disability Inclusion in Hospital Disaster Risk Management4, using the Spanish acronym INGRID-H, which is a "evaluation - action" methodology intended to improve the level of inclusion of PWD in health disaster risk management, Mexico was one of the countries that collaborated in this development, and IMSS has been applying this methodology to accomplish the inclusion of PWD.

INGRID-H

INGRID-H[4] aims to improve the level of preparedness in hospitals responding to emergencies and disasters with emphasis on PWD in the hospital setting, and its objectives are facilitate the capacity of PWD (autonomy), promote the strengthening of hospital capacities to support PWD, and identify critical points and decision-making to increase the level of inclusion[4].

Mexican Social Security Institute and Disability

Since 2008, IMSS has stablished the Institutional Committee for the Rights of PWD, this Committee includes in its organization not only IMSS staff, and it also includes PWD and disabled people's organizations (DPOs) as contributing stakeholders.

One of Committee achievements was the development of the Architectural project criteria for the accessibility of PWD, this criteria has been applied not only in IMSS infrastructure, it has been an example for the Project for the homologating criteria and en-

suring access and displacement of persons with disabilities in all the buildings of the government whether they work in them, or are in the process of providing a service or procedure.

Nowadays INGRID-H was presented to the Committee with the purpose to include this issue in its work plan and in the future it could be applied in primary care facilities or adapted to other IMSS infrastructure such as nurseries, theatres and vacation centers.

Material and Methods

The INGRID-H facilitators who support the evaluation took the facilitators course approved by PAHO/WHO, and they instructed and guided hospital staff to apply the methodology, present the results and analyze them, and create the action plan.

Physical and Rehabilitation Medical Unit "*Villalongin*" was the facility where INGRID-H was applied. This is a monothematic facility, 90% of their patients are people with temporal or permanent disability, and it has 50 beds for patients who need rehabilitation and their principal diagnosis are medullar lesions. During 40 days the patients and their relatives learn about their inclusion in the society (back to school, work, use of transportation, use of wheelchair, etc.)

INGRID-H methodology divided into three phases4: evaluation sets the current level of inclusion of PWD in the hospital; visibility, participation and response capacity activities; and verification, where actions are established and inclusive drills were conducted.

Following these phases, we present the results for each one and most importantly, an analysis about how much the facility has to invest to be inclusive.

Results

In the first Evaluation phase, facilitators visited the unit with the hospital staff; they reviewed the hospital disaster plan, the Hospital Committee on Emergencies, emergency exits, alarm system, and made interviews with patients and its companions, made questions to health workers about inclusion, what to do in emergency, and how they help PWD in an emergency. All this activities allowed evaluate five aspects: visibility and participation of PWD, universal accessibility, capacities developed for disaster response and finally the hospital plan for response to emergencies and disasters. Once the visit was finished, facilitators and facility's staff completed the formulary, then the mathematical model was applied so the system could create a radar chart (Figure 1) and we could observe the levels of inclusiveness in hospital disaster risk management, by evaluation component, and we could conclude that the levels of inclusiveness of the facility were 18.86%, which means non-inclusive.

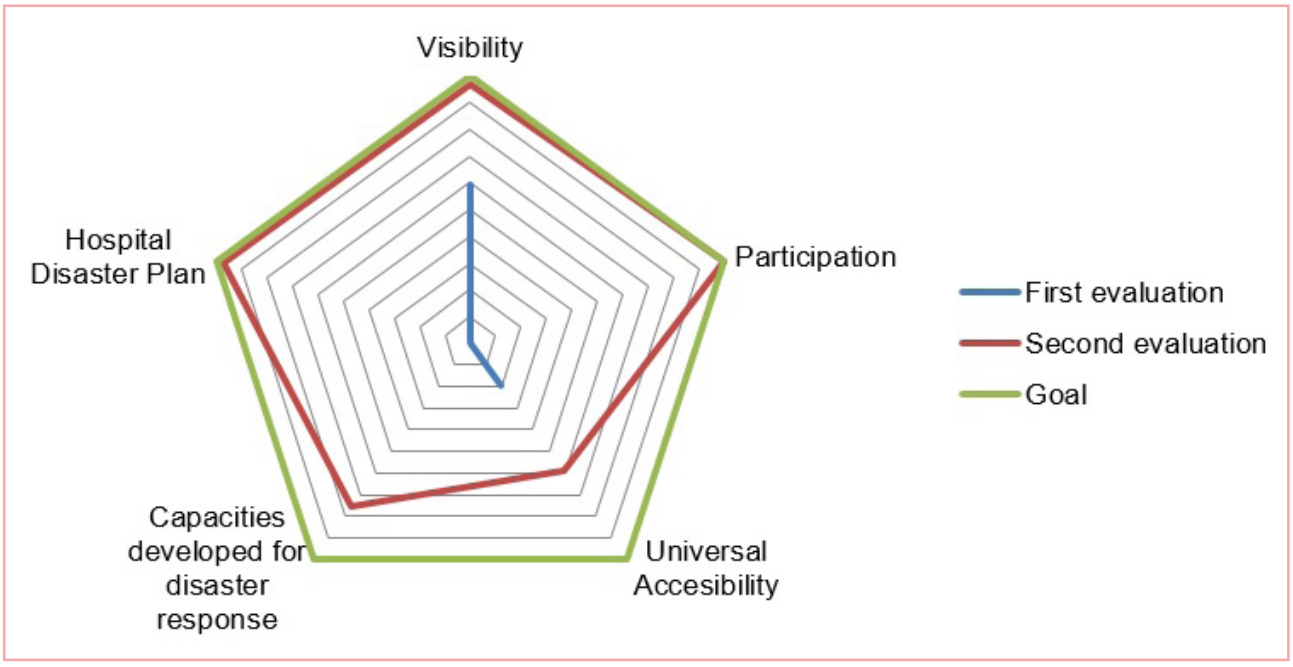

Figura 1. Levels of inclusiveness in hospital disaster risk management, by evaluation component.

According to INGRIDH[4] methodology cycle, we must complete other achievements at 30 days (VP-30) and 180 days; but for this review we presented only the results at 180 days, when another visit to evaluate and verify the progress to improve the civil protection culture and provide guarantees about inclusion of PWD, through the execution of inclusive simulations and drills, with an emphasis on the

disability variable. Some of the main activities done during this period are resumed in table 1. In figure 1 we can observe the radar chart and how it changed the qualification for the five components and achieved a level of inclusiveness of 86.12% which means inclusive.

Through the analysis of what interventions have to be done to change that index, the most important actions were based on very low cost activities or simply with courses about proper conduct and response in emergency and disasters. In table 1 we describe the activities and the estimated cost was approximately $2,860 dollars.

Tabla I
Activities and intervention did by facility staff

Aspects evaluated	Activities and intervention
Visibility	Records about workers, patients and visitants with disability or with vulnerability in case of an emergency or disaster situation.
	Daily record and obligatory registration for access to the facility.
Participation	Integrate a PWD in the Hospital Committee on Emergencies.
	A PWD participates in the simulation and drills.
Universal accessibility	Adequate signals for the evacuation routes (40 arrows were placed on the floor and 40 on the walls to guarantied an adequate Access to the safe area and meeting points)
	A new design and identification for emergency exists, including the identification of indoor safe areas.
	Installation of six visual and sound alarms.
Capacities for disaster response	To share INGRID-H results.
	Training of staff, patients and brigadiers in INGRID-H methodology and care of PWD in emergencies or disasters.
Hospital Disaster Plan	Updating the response plan with inclusion approach, aligned to the recommendations of Safe Hospital Program.
Verification	The hospital staff organized three drills, in all of them PWD were included.

Another result obtained was if the facility with the actual conditions allows PWD to respond in case of emergency or disaster with autonomy and if the facility had the capacity for an adequate response; placing the hospital in one of four possible inclusive risk management scenarios (figure 2). In figure 3 we compared the results for the first and second evaluation. The first result show that the facility was in quadrant D (PWD) are considered to be highly vulnerable in emergency situations), and in the second evaluation

Figura 2. Drills where PWD were included. In the picture we can observe the signals on the floor.

it was positioned in the quadrant A (PWD can inform themselves, move about, and evacuate in emergency situations, whether autonomously or with the assistance of personnel assigned for this purpose)

Discussion

It is important to note that a lot of IMSS hospitals were constructed before the establishment of safe hospital program in Mexico, and when they were constructed there was not legislation about inclusion, equity or disability. This is the first reason why we need to implement a program to evaluate the level of inclusiveness and to start a change in this matter.

IMSS has a history in disaster risk reduction through Safe Hospital Program implementation, but when we started to review the factors and characteristics of inclusion, disability and PWD, we found a great gap and the urgent necessity to work in this issue, like accessibility, visibility and how to include PWD in disaster risk management activities.

Disaster risk management should take account of all people, with special emphasis on those who are most vulnerable or require priority attention. In the recent time, PWD were been excluded from disaster management process, unable to access materials about what they have to do in case of emergency or disaster, and we do not understand that only them are capable of meeting their vulnerabilities and providing advice on disaster mitigation planning. But maybe we must first change our vision of vulnerable; for example Lee and Chen[14] suggest the vulnerability approach sees the vulnerable population as a social construction of disasters and people as passive victims rather than active participants capable of shaping the process of disaster management, therefore PWD should not be seen as people in a vulnerable situation, and understand that they have the capacity to be part of the disaster management process[15]. In this case we have to start seeing disability as a social construction, and not only the deficiency created by society, they have the ability to decide or to design autonomously their own life plan with equal opportunity[16].

A lot of times during an emergency or disaster we look at disability related only to evacuation out of the building and the need of mobility, for this we can found studies and strategies on evacuation of people with wheelchairs or limited mobility[17], but this is not inclusion, at least we have to encourage the visibility and participation of these people, knowing what they need and how we can help them in this situations. King[18] describes the barriers to disability-inclusive in disaster management and one of the participants in his study said: "*I think because they believe they don't have the ability of doing things, but they are wrong, people with disabilites, they have abilities to do things as well*". In order to expand the capabilities of PWD, they should participate in decision-making processes influencing their well-being and safety in times of disasters[19].

Whit the sponsorship of PAHO/WHO we applied INGRID-H4, and our findings demonstrated that in

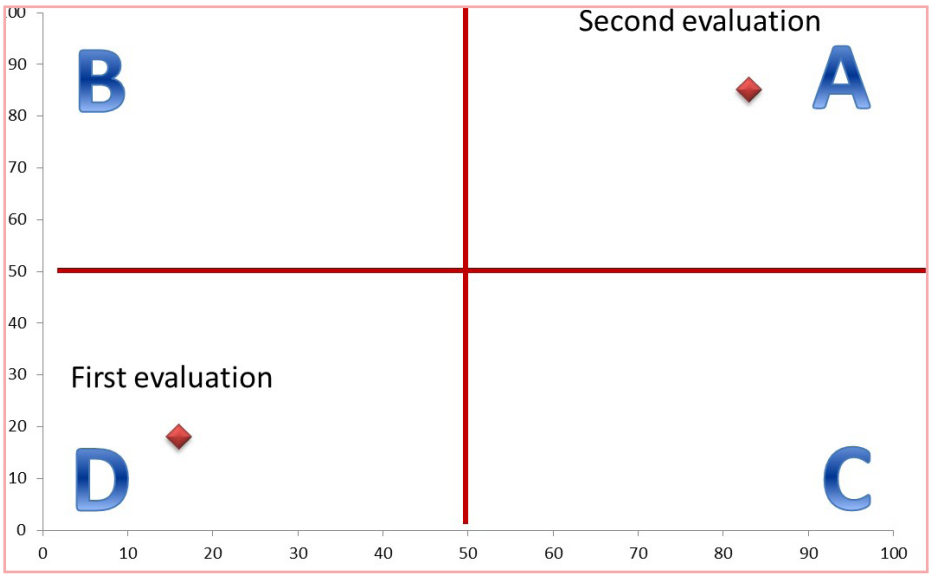

Figura 3. Inclusive risk management scenarios.

our disaster risk management the concept of inclusion does not exist, maybe an approximation of what accessibility is but not all the characteristics and aspects needed to have a culture of inclusion of PWD. Through this methodology we learned how to change discriminatory conducts and respect human rights of PWD from the point of view of disaster risk management.

In this case, we could observe how non-expensive disability-inclusive interventions could change the facility INGRID-H index[4] from non-inclusive to inclusive, only making changes in little aspects like warning systems and signals, and these interventions have the potential to benefit everyone thanks to the application of accessibility standards and universal design. For example, the more people are reached by early warning systems, the more they can maximize the time pre-disaster to effect evacuation or shelter-in-place plans, thus increasing their chances for survival, and potentially giving them time to protect assets such as homes, livestock, and transportation. In a study of Park et al[20], they found that barrier-free disaster information is a basic need for all members of society, and conclude "*disaster evacuation literature highlights how clear, specific information from the central or local governments, or via the mainstream broadcasting system, is a significant factor in successful evacuations and the government must provide an adequate disaster alarm system for persons with visual and hearing impairments*". In our experience, sharing information was the most important action because it allows everybody to know about what to do, and how can they help or how someone can help them, but include PWD in the Hospital Committee on Emergencies is an example of how they can participate in the decision process about what to do in emergency or disaster.

Another example about the benefits observed by INGRID-H implementation was that all the stakeholders participated after learning about disability and the education on knowhow disaster-awareness capacity building that is linked to disability issues. Education is a priority when we talk about disability. INGRID-H allows educating to not only the hospital´s staff, but it also includes PWD. In the Survey on Living with disabilities and disasters[21] made by UNISDR (United Nations Office for Disaster Risk Reduction) in 2013, we can find the desire of people, communities and responders to educate, sensitize and train on what to do in an emergency with PWD.

A lot of times we can misconceive the term accessibility by just thinking that a hospital has ramps and obstacle-free paths, but in reality we might find that the facilities had been built before all this culture about inclusion exist, that could be an explanation of why the halls are affected by obstacles that hinder mobility, and the lack of curb ramps causing the highest impact on accessibility. We need to understand that universal accessibility must allow everybody to use the same hall, the same elevator or the same ramp, all the facility´s services must be safely, autonomously, and easily understood and used by all people. Therefore the new hospitals should be conceived or planned from the start, as well as used, by all people to the greatest extent possible. And we need more studies focused on the accessibility of PWD in public spaces[15, 22].

Conclusions

People with disabilities are frequently at risk or affected disproportionately in disaster situations, emergencies and conflicts due to various factors. The implementation of INGRID-H will not only contribute to the fulfillment of the rights of PWD, but will also

contribute to the efforts to have a safer, more inclusive and resilient health sector.

Raising awareness, fighting negative attitudes, and addressing discrimination would reduce vulnerability and result in better outcomes during disasters for all people.

In the example we showed the results of a methodology to evaluate the inclusiveness in a facility where 90% of the patients were PWD, and how the main changes to make are visibility and participation.

We need more studies evaluating cost-risk-benefits about the investment in inclusiveness, and evaluating the participation of PWD in drills and in real life.

Changes in legal framework and normativity are the first step, and our work will be focus on applying this methodology in all the IMSS's medical units.

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