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Leaving No One Behind in Indonesia: Protecting the Rights of Persons with Disabilities in Disadvantaged and Remote Areas

A contextual systems framework

Foreword

Ensuring human rights and prosperity for everyone is fundamental to genuine development. The core principle of the United Nations' Agenda 2030 is to create a fairer and more sustainable world, encapsulated in the ethos of **“Leave No One Behind”** (LNOB). This commitment is not just a moral obligation, it is a concrete and practical strategy for achieving the Sustainable Development Goals (SDGs), with a focus on lifting people out of poverty or oblivion.

In Indonesia, as in many middle-income countries, the pursuit of leaving no one behind requires a deep understanding of the challenges faced by groups who are marginalized despite considerable economic and social progress in the society as a whole. This research study conducted by the UN in Indonesia sets out to understand these challenges in order to, ultimately, inform policymaking.

It is a continuation of our previous study *Leave No One Behind in Indonesia*; A data-driven study identifying inequalities and discrimination faced by those furthest left behind, conducted in 2022, which identified left behind populations, highlighting people living in rural and disadvantaged areas as the most vulnerable, among them persons with disabilities as the furthest left behind. This second LNOB study of focuses specifically on the challenges encountered by persons with disabilities in disadvantaged areas. It seeks to understand the systemic barriers they face in accessing essential services such as healthcare, education, as well as economic opportunities, social inclusion



and political participation. By analyzing the root causes of marginalization and evaluating existing capacity gaps, this study sets out to provide concrete policy recommendations to protect the rights and promote the inclusion of persons with disabilities.

The meticulous approach taken by the UN in Indonesia in conducting this study is commendable. A strategic review was undertaken to comprehensively understand the national policy landscape, followed by extensive fieldwork in West Sumba, East Nusa Tenggara (NTT) and Jayawijaya, Highland Papua. The immersion of UN community volunteers into these local contexts has yielded invaluable insights, aptly termed as warm data, which illustrates the interconnected relationships of social-environmental pressures on the people living in these remote areas.

The findings of this study do not only shed light on the challenges faced by persons with disabilities but also provide strategic points of influence for a comprehensive transformation towards inclusive development. From adopting a rights-based approach to developing contextual bottom-up solutions, and an operational guide, this research underscores the importance of collaborative efforts in ensuring that no one is left behind.



Valerie Julliard

United Nations Resident Coordinator for Indonesia

In my capacity as the Resident Coordinator, I commend the dedication and commitment of all those involved in this study. It is my hope that the insights gleaned from this research will inform policy decisions and interventions aimed at building a more inclusive and equitable society for all Indonesians.



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The study greatly benefitted from the thought leadership and comprehensive supervision of Valerie Julliard, the UN Resident Coordinator Indonesia, along with strategic and management counsel from Afke Bootsman, the Head of UN Resident Coordinator's Office (RCO).

The lead researcher conducting this LNOB study was Yulia Sugandi, an anthropologist and sociologist affiliated with the Center for Transdisciplinary and Sustainability Sciences, IPB University. The research team comprised Fajri Ilham Mughni, Yefta Lengka (a UN Community Volunteer in Jayawijaya), and Fridolin Umbu Manna Masarani (a UN Community Volunteer in West Sumba).

The RCO and UNV committed teams were instrumental in obtaining rigorous study findings through effective collaboration. Arben Sejdaj, the Leaving No One Behind Officer, ensured the study's excellence through coordination among the United Nations system in Indonesia. Diandra Pratami, Economist, supported efficient research management and contributed to the editing of the study. Mazayannisa Suyuthi, Volunteerism Mainstreaming Officer offered managerial support to UN Community volunteers. Erlangga Landiyanto, the Data & Results Monitoring

Evaluation Officer, assisted in the recruitment of UN Community volunteers. The involvement of UN agencies in different phases of the research, such as the immersion methods workshop and the sense making workshop, proved to be an invaluable contribution to this study.

The study participants' openness and trust greatly influenced this research, as they generously shared their insights and collaborated with UN Community volunteers during the immersion of West Sumba and Jayawijaya. Their commitment and eagerness to co-create knowledge has significantly deepened our understanding of the local context. Apart from that, this study also received valuable input through in-depth interviews with various sources consisting of disability inclusion activists and experts, government officials, a sign language interpreter, disability centers in universities, research institutions, CSOs and Organizations of Persons with Disabilities.

Also recognized here are the contributions of Marsa Dhiya Millatina, who provided skills in graphic design and layout for the study report, with consultative support from Eunjoo Lee, Programme Officer with RCO, and of Miklos Gaspar, the Director of UNIC, in disseminating the study results.



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Glossary and Abbreviation

Ableism	The negation of diversity in the processing of knowledge, discrimination and prejudice directed towards individuals with disabilities
Adat	Customary law of the indigenous peoples of Indonesia
Area of Conversation (AoC)	Serve as a guide for informal discussions and participatory visuals during immersion
ASF/AFH	African swine fever (ASF), highly contagious and usually fatal viral disease of swine that is characterized by high fever, lesions, leukopenia (abnormally low count of white blood cells), elevated pulse and respiration rate, and death within four to seven days after the onset of fever
ASN	The State Civil Apparatus
Ata	Ata or Tau La uma literary means “in house people” or slaves
ATM	Automated Teller Machine
Bappenas	Ministry of National Development Planning of the Republic of Indonesia
Biomedical Model	Adheres to a linear perspective that views impairment as an internal issue within the individual, failing to acknowledge the complexities of social inclusion
BISINDO	Indonesian Sign Language
BKKBN	National Family Planning Coordination Board
BMKG	Indonesian Agency for Meteorological, Climatological and Geophysics
BNPB	The National Agency for Disaster Countermeasure
BPS	Statistics Indonesia
BRIN	National Research and Innovation Agency
Cacat	The state of being badly shaped or formed
Caste System	A complex web of oppression, with a particular focus on the close yet unequal interactions between slaves and nobles
Cold Data	Quantitative data or metrics that capture a single variable at a time, at a single point in time
CRPD	Convention on the Rights of Persons with Disabilities
DOB	New Autonomous Region
Domino Effect	The situation in which something, usually something bad, happens, causing other similar events to happen
DPR	The Indonesian House of Representatives
Emic	Insider perspectives and experiences from the end users
Etic	External knowledge and expertise

FSVA	Food Security and Vulnerability Atlas
GRDP	Gross Regional Domestic Product (GRDP) is the aggregate of gross value added (GVA) of all resident producer units in the region
HIV	HIV, retrovirus that attacks and gradually destroys the immune system, leaving the host unprotected against infection. HIV is classified as a lentivirus (meaning “slow virus”)
HRBA	Human Rights-Based Approach
HRBAD	Human Rights-Based Approach to Development
IDP	Internally Displaced Person is someone who is forced to leave their home but who remains within their country's borders
IKP	Food Security Index
ILO	International Labour Organization
Immersion	Deep mental involvement and is done by opening oneself to understand and feel the in-depth context by applying experiential learning and informal conversations
Social Inclusion	The deliberate action of accommodating and considering the perspectives and viewpoints of individuals within a social setting
Indigenous Ritual	Rituals performed by indigenous communities to achieve equilibrium and serenity within a complex web of connections
Sumba Indigenous Slavery	Custom of slavery that is innate in Sumba society with slave-owners and slaves coming from the same Sumbanese ethnic background
IOM	International Organization for Migration
IPBES	Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services
Ka'biyu	The commoner class in Sumba caste system
Kelompok Rentan	Vulnerable groups
KK	Family Card
KND	National Commission on Disabilities
Kontras	Commission for Missing Persons and Victims of Violence
KPU	General Election Commission
KTP	ID Card
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual and other sexually or gender diverse
LNOB	Leave No One Behind
Maramba	The noble caste
Marginality	The state or condition of being isolated from and not fully accepted by the dominant society or culture, and therefore frequently disadvantaged
MCK	Public bathing, washing and toilet facilities
UNESCO	United Nations Educational, Scientific and Cultural Organization

NCD	Non Communicable Diseases
UU Cipta Kerja	Omnibus Law on Job Creation
OPDs	Organizations of Persons with Disabilities
PANEL	Participation, Accountability, Non-discrimination and Equality, Empowerment, and Legality
PIP	Smart Indonesia Program provides incentives for all children to complete at least a 9-year basic education
PKH	Family Hope Program that provides conditional social assistance to underprivileged families
POSBINDU PTM	Integrated Development Post for Non-Communicable Diseases
Puskesmas	Community Health Center
PWD	Person With Disabilities
Raskin	A subsidized of rice program for poor families
Cultural Resilience Framework	It considers how cultural background (i.e., culture, cultural values, language, customs, norms) helps individuals and communities overcome adversity
RUU	The bill of law
SDGs	Sustainable Development Goals
SIBI	Indonesian Sign Language System
SOP	Standard Operating Procedure
Stroke	Sudden impairment or loss of consciousness, sensation, and voluntary motion that is caused by rupture or obstruction (as by a clot) of a blood vessel supplying the brain, and is accompanied by permanent damage of brain tissue
PP	The Presidential Decree
TNP2K	National Team for the Acceleration of Poverty Reduction
Transcontextual	Multiple different contexts that are interconnected and interdependent behind any single question, issue or thing we look at
UN Community Volunteers	UN volunteers who work where they live on projects impact their own community
UN Women	United Nations Entity for Gender Equality and the Empowerment of Women
UN/DESA	United Nations' Department of Economic and Social Affairs
UNCT	United Nations Country Team
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
UNSDG	United Nations Sustainable Development Group
UPR	Universal Periodic Review

UU	Act, Law
Warm Data	Transcontextual information about the interrelationships that connect elements of a complex system
WASH	Water, Sanitation, and Hygiene
Well-being	What is intrinsically valuable relative to someone
WFP	World Food Programme
WHO	World Health Organization



Executive Summary

As part of the follow-up study on Leave No One Behind (LNOB), the United Nations Country Team (UNCT) in Indonesia conducts a comprehensive contextual assessment to delve deeply into the resilience of the system from the perspective of marginalized groups who have been excluded from the mainstream system, with a specific focus on persons with disabilities residing in disadvantaged regions.

This study is a continuation of [a previous study](#) on left behind groups and their inequalities and discrimination. The first phase of the study in 2022 successfully identified left behind populations in Indonesia using quantitative and qualitative analysis. The study revealed that older people and persons with disabilities in disadvantaged areas are the most left behind. Intersectional factors further increase the risks for these groups. Exclusionary processes contribute to their vulnerability, including marginalization of indigenous peoples and discrimination against people living with HIV, LGBTIQ+ individuals, and gender diverse communities. Qualitative analysis of the initial study identified factors that cause marginalization of persons with disabilities, such as systemic barriers,

inadequate financial resources, ineffective law enforcement, limited awareness in the public sector, and conflicting data.

Based on these findings, this second phase study aims to explore the challenges faced by persons with disabilities in disadvantaged areas. The study will address the primary question of why people with disabilities in these areas encounter the most difficulties in accessing healthcare, education, economic well-being, social opportunities, public/civic spaces, and political inclusion. By referring to the Good Practice Note for UNCT on Operationalizing Leaving No One Behind (LNOB) in 2022, this study will thoroughly investigate the underlying causes, analyze role patterns, and evaluate capacity gaps. The objective is to provide policy recommendations and practical steps to protect the rights and promote the inclusion of persons with disabilities.

In order to gain a comprehensive understanding of the national policy landscape, a strategic review was meticulously conducted, employing a combination of document analysis and in-depth interviews as the primary methods of data collection. This initial

step played a crucial role in understanding about structural landscape on the complex dynamics and nuances within the national policy framework. Following that, a team of dedicated UN community volunteers embarked on an extensive fieldwork endeavor in West Sumba-NTT and Jayawijaya-Papua. These volunteers wholeheartedly immersed themselves in the local context, actively engaging with the communities and meticulously documenting their experiences. This immersive method yielded a wealth of firsthand data, aptly referred to as "warm data," which provided a nuanced and vivid portrayal of the intricate interrelationships that exist between various components of the social-ecological system. Through this comprehensive data collection process, the study was able to effectively capture and elucidate the multifaceted dynamics that underpin the resilience of the system, while shedding light on the lived experiences and challenges faced by persons with disabilities in disadvantaged areas.

The strategic review's results of documents and interviews have provided a comprehensive understanding of the complex structural landscape. It has shed light on crucial aspects such as the interconnectedness between mindset, stigma, disability paradigm, and data quality and governance. These relationships impact the fulfillment of basic rights and the well-being of persons with disabilities. Changes in laws without a rights-based paradigm transformation and contextual data result in irrelevant policies for protecting the rights of persons with disabilities. Inclusive development still needs indicators that

capture the system's complexity and achieve meaningful participation from affected groups.

In the meantime, it is important to note that the contextual landscape in West Sumba & Jayawijaya has significant aspects that require attention. The interrelationship between various elements within the system plays a crucial role in determining accessibility for persons with disabilities. Inclusion processes that do not consider non-economic indicators cannot fully uncover the causes of unequal opportunities. Addressing barriers horizontally and vertically is crucial in breaking the cycle of disability and deprivation. Identifying positive deviance and understanding environmental pressures can lead to positive change. The contextual landscape in West Sumba & Jayawijaya provides opportunities to improve the lives of persons with disabilities.

The mentioned results generate strategic points of influence for a comprehensive transformation of the system to achieve inclusive development, benefiting all individuals including marginalized communities. These points consist of adopting a rights-based approach, using warm data, involving affected communities, recognizing social and environmental pressures, considering non-economic indicators, and implementing agile and adaptive governance. In addition to that, the UN community volunteers in West Sumba and Jayawijaya systematically developed contextual bottom-up solutions.

CHAPTER 1

Introduction

Inclusion, HRBA and Systems Thinking





1. Introduction: Inclusion, HRBA and Systems Thinking

“Human rights are at the heart of the 2030 Agenda and SDG 16 is the lever to effect transformative change for the rest of the Goals,” said UN Assistant Secretary-General for Human Rights, Ilze Brands Kehris. “That is why this important report urges all States to accelerate progress towards achieving SDG 16, while also calling for new partnerships to stimulate the compilation and use of human rights statistics. Harnessing data on the protection of human rights defenders who denounce environmental, social, or political rights abuses – as well on all people against discrimination, violence, and lack of access to justice or participation – is crucial to delivering on our commitments to leave no one behind”¹.

HRBA is a programming tool intended to strengthen the quality and focus of UN responses to national priorities. It is normatively based on international human rights standards and principles and operationally directed to promoting human rights. HRBA is based on human rights obligations that countries have committed to and have a legal obligation to fulfil. Under a human rights-based approach, the plans, policies, and processes of development are anchored in

a system of rights and corresponding obligations established by international law, including all civil, cultural, economic, political, and social rights, labor rights and the right to development. LNOB deepens focus on the inequalities, including multiple forms of deprivation, disadvantage, and discrimination, and "reaching the furthest behind first". HRBA brings to the LNOB a rigorous methodology for identifying who is left behind and why, looking at root causes. three-step process for the analysis and assessment stage of programming that identifies who is left behind and why: causality analysis, role analysis, and capacity gap analysis. The methodology of HRBA brings to LNOB a focus on rights, empowerment, meaningful participation, and capacity development (UNSDG, 2022).

The objective of reaching the most impoverished individuals in society is not the sole aspect of Leaving No One Behind (LNOB). It also encompasses the imperative task of addressing discrimination and the widening gaps in equality within and between nations, as well as understanding the underlying factors contributing to these issues. To ensure that no individual is marginalized, it becomes essential to undertake a profound transformation of deeply ingrained systems, encompassing economic, social, and political structures, governance frameworks, and business models across all levels, ranging from local

¹

<https://www.undp.org/press-releases/progress-peace-justice-and-inclusion-dangerously-track-new-un-report-calls-urgent-action-achieve-sustainable-development-goal-16>

to global. Failing to undertake such a comprehensive endeavor will result in persistent disparities across different regions and countries (UNSDG, 2022),

which underscores the significance of systemic actions from diverse stakeholders and societal levels.

COMPLEMENTARITIES

HRBA	LNOB
<p>HRBA is a programming tool intended to strengthen the quality and focus of UN responses to national priorities. It is normatively based on international human rights standards and principles and operationally directed to promoting human rights.</p>	<p>Addressing inequalities is central to the 2030 Agenda. LNOB is a guiding principle of the 2030 Agenda, which is itself explicitly grounded in international law, including human rights.</p>
<p>HRBA is based on human rights obligations that countries have committed to and have a legal obligation to fulfill. Under a human rights-based approach, the plans, policies and processes of development are anchored in a system of rights and corresponding obligations established by international law, including all civil, cultural, economic, political and social rights, labour rights and the right to development.</p>	<p>LNOB is a political commitment that states committed to when they signed on to the SDG Agenda.</p>
<p>HRBA has a clear three-step process for the analysis and assessment stage of programming that identifies who is left behind and why: causality analysis, role analysis, and capacity gap analysis.</p>	<p>LNOB deepens focus on the inequalities, including multiple forms of deprivation, disadvantage and discrimination, and “reaching the furthest behind first”. HRBA brings to the LNOB a rigorous methodology for identifying who is left behind and why, looking at root causes.</p>
<p>Both require a disaggregated data to identify who is "left behind" and why, and to determine whether development interventions are reaching these groups and addressing the gaps.</p>	
<p>The human rights principles of Non-Discrimination and Equality are key elements of a HRBA and LNOB approach. Both require proactive measures to address inequalities, reaching the furthest behind first.</p>	
<p>In both, addressing gender inequalities is a priority</p>	

<p>HRBA focuses on empowerment of "right holders" to claim their rights and empower them as active partners in development, ensure their voice in the process; and mobilize, etc.</p> <p>HRBA also focuses on capacity development of "duty-bearers" to meet their obligations.</p>	<p>Methodology of HRBA brings to LNOB a focus on rights, empowerment, meaningful participation and capacity development.</p>
<p>Under both, free, active and meaningful participation is promoted throughout the entire planning and programming process</p>	
<p>Under HRBA, the international human rights mechanisms can provide a valuable opportunity for strengthening the accountability of Government to address marginalization and inequality.</p>	

The analysis of causality, analysis of role, and analysis of capacity gap that are presented in this study report are situated within the conceptual framework of systems thinking. Systems thinking is distinct from analytical thinking. When we engage in analysis, we deconstruct entities to acquire knowledge of their functioning. While the answer to a question in analysis lies within the subject we study, in systems thinking, it lies outside the subject. Systems thinking entails an inward-outward perspective; it is a cognitive approach characterized by a comprehensive outlook on the world, signifying that we consistently examine phenomena in relation to the entirety they constitute a part of. When we seek to comprehend the situation of persons with disabilities in disadvantaged and remote regions, we strive to gain an understanding within the broader framework in which these individuals are situated. This involves examining various levels, starting from the smallest unit of the system, which is the family or household, and extending to the surrounding environment and even the national policy context.

It is widely acknowledged that most policy challenges emerge within intricate systems that are continuously evolving, characterized by a high degree of uncertainty and an intricate web of cause-and-effect relationships. These systems are composed of a multitude of components, interconnections, stakeholders, and drivers, and it is often the case that the perspectives of these stakeholders do not align. In some instances, even defining the policy problem itself can be a complex task that poses a significant challenge to fully grasp, let alone explore potential solutions to effectively address the problem.

Instead of perceiving a system as a mere aggregation of its individual components, the approach of systems thinking seeks to perceive each part as an indispensable element of the entire system, placing great emphasis on the critical nature of the connections that exist between these elements. By deconstructing complex problems into smaller, distinct parts, the application of systems thinking enables us to discern the interrelationships among these parts and thereby enhance the

likelihood of achieving positive, intentional outcomes. The main characteristics of systems thinking are centered around giving priority to the relationships between various components rather than just focusing on the individual components themselves. This approach aims to shed light on the complete range of possibilities that exist within a given system, instead of relying solely on convergent thinking which tends to narrow down the options.

Additionally, the focus is on understanding the system as a whole, rather than analysing the individual properties in isolation. Instead of taking a static view of the world, systems thinking emphasizes the study of dynamics and how they shape the behavior of the system. Moreover, it involves examining open systems as opposed to closed ones, recognizing the importance of external influences and interactions. With this comprehensive approach, systems thinking allows us to deeply consider the interconnectedness of various factors within the system, including social and environmental pressures. By carefully studying these connections, we can identify patterns of organization and gain insights into how system behavior emerges from these interactions. This emphasis on interconnections not only helps us understand the complex dynamics of the system, but also allows us to appreciate how they impact the accessibility of basic needs for persons with disabilities.

Innovation and systems thinking have the capacity to assist in the process of identifying the underlying causes of complex problems by going beyond the surface-level symptoms and addressing the systemic issues that lie beneath them. When one engages in systems thinking,

they are able to grasp a deeper understanding of the fundamental causes of complex problems and subsequently develop comprehensive solutions that effectively tackle the systemic issues that underpin them. This encompasses various organic solutions known as positive deviance (PD) that are generated by communities impacted by social and environmental pressures. The concept of positive deviance stems from the recognition that within any given community, there exist individuals or groups who possess unique behaviors and strategies that allow them to discover more effective problem-solving approaches compared to their counterparts, even when they have access to the same resources and confront similar or more difficult challenges.

The process of resolving complex problems requires intervening in a intricate system, where the issue at hand is not seen as an isolated problem but rather acknowledged as a multidimensional obstacle. It is crucial to comprehend that there exist a multitude of factors, interrelated problems, and multiple root causes that must all be taken into account when attempting to address complex problems. Given the intricate nature of these problems, it becomes imperative to adopt interdisciplinary solutions that involve the participation of various stakeholders, including experts from diverse fields. By embracing innovation and systems thinking, one is able to cultivate an environment that encourages the integration of different perspectives and the development of collaborative solutions that effectively tackle the intricate challenges posed by complex problems.

The adoption of a systems thinking approach empowers us to uncover and

comprehend the underlying causes of problems and assess the potential impacts of any proposed solutions on the broader system. Although there may still be the possibility of unintended consequences, the implementation of systems thinking allows us to minimize this probability. By

considering the entirety of the system and fully comprehending the interconnections between its various components, we can design policies that possess the necessary flexibility and adaptability to effectively accommodate future changes within the system (Slater 2023).

Disability inclusion is part of inclusive social development pillar and related policy agenda. What is meant by social inclusion or social exclusion? In order to support qualitative analysis and design of inclusive policies of more inclusive, equity-weighted and SDG-oriented policies, it is necessary to pay attention to the elements of meaning attached to social exclusion (MOST UNESCO, 2015):

- a. **Multidimensional:** social exclusion concept comprises of social, civic, political, cultural and economic dimensions
- b. **Dynamic:** social exclusion is not a static state experienced. The exclusionary processes happen in different ways, degrees, intensity and social levels
- c. **Relational:** inability to enjoy shared opportunities due to unequal social relationships characterised by differential power
- d. **Contextual:** the inability to participate and enjoy economic, social and civic opportunities shaped by cultural, institutional and socio-economic factors
- e. **Multiple levels:** definitions refer to different levels along which social exclusion/inclusion operates, namely micro (e.g., individual, household), meso (e.g., neighborhoods) and macro (i.e., nation state and global regions)
- f. **Group and individual approaches:** group-based identifies excluded groups and factors that cause social exclusion, whereas Individual characteristics that place a person at risk of social exclusion are gender, ethnicity, language, religion, age, sexual orientation, religious beliefs, disability and status (income, health, employment, education, resources, opportunities and assets)
- g. **Drivers:** social exclusion resulted from interaction of risks with a set of drivers (i.e. structural, behavioural, or policy-related)

The concept of social exclusion and inclusion is highly dependent on the specific context in which it is analysed, and this can be understood in at least three different ways. Firstly, when considering the normative aspect, the perception of an inclusive society can vary greatly depending on the dominant image, framework, ideal, or paradigm that is upheld. Secondly, different geographical locations have distinct histories, cultures, institutions, and social structures, which

means that certain dimensions of social exclusion, whether they be economic, social, or political in nature, may hold more significance and be more impactful than others. Lastly, the context in which an individual resides plays a crucial role in determining their level of social inclusion, as it shapes their access to resources and social connections. By acknowledging the variation in meaning and manifestations of exclusion and inclusion across different contexts, we are not negating the

influence of globalization trends in generating exclusion. Rather, we are emphasizing the importance of national and local solidarities and institutions in mediating these trends and giving rise to unique patterns in different places. It is worth noting that due to the persistence of ideas and institutions within a specific location, the distribution of inclusion is not uniform across space.

When adopting an analytical approach that aims to simplify and break down data into its individual components, there is often a tendency to arrive at conclusions that fail to fully grasp the complexity of the situation at hand. This occurs because this method neglects to consider the intricate interrelationships that exist within a given system, thereby leading to misguided decision-making and unfavorable outcomes. In order to prevent the occurrence of these blind spots, it is crucial that we supplement the existing data with contextual information. While a reductionist approach seeks to eliminate context and focuses solely on measuring changes in isolated parts within a constant environment, it is important to recognize that when it comes to bringing about systemic change, it is the context that must be thoroughly evaluated and understood.

The process of comprehending context on a micro level encompasses the principles of complexity, which in turn enables us to gain a deeper understanding of the diversity and inequality that exists not only between different groups, such as those with disabilities and those without, but also within these groups through horizontal inequalities. Horizontal inequalities refer to the disparities that arise among groups who share a common identity, and they represent one of the most significant forms of inequality due to

their impact on justice and social stability. Examples of group categories that are relevant in the context of horizontal inequalities include race, ethnicity, religion, class, gender, and age (Stewart 2016).

To illustrate this further, let's consider the situation of indigenous women who experience severe physical disabilities and reside in impoverished remote areas where access to healthcare services is limited. In addition to these challenges, these women also face the oppressive influence of patriarchal norms that are deeply entrenched in their communities, as well as the stigma and shame associated with disabilities. Consequently, these women are at a higher risk of social exclusion compared to women who have similar disabilities but benefit from a higher social standing, possess better social security, and enjoy a more supportive environment. Horizontal inequalities offer a comprehensive insight into the multiple barriers that exist within a group, encompassing various intersectional variables, thereby facilitating a thorough comprehension of the complex dynamics at play. It is through this understanding that the groundwork is laid for the development and implementation of appropriate and targeted interventions that are specifically tailored to address these specific challenges, while ensuring inclusivity and fairness for all members of the affected group.



CHAPTER 2

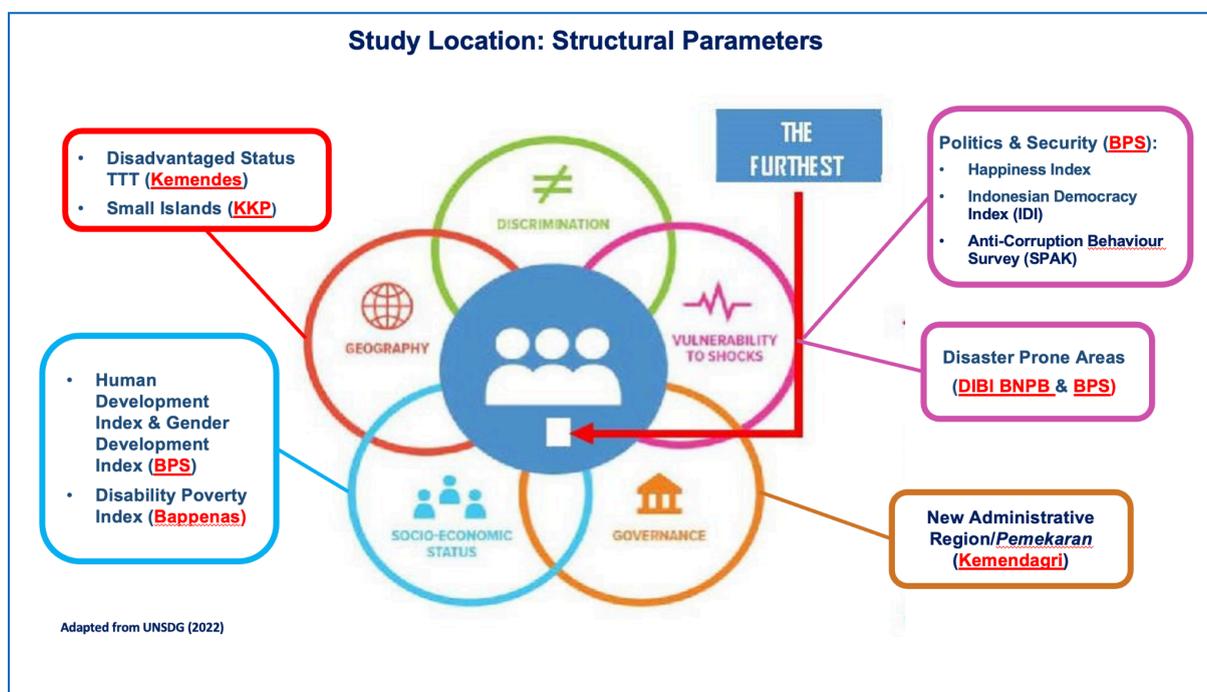
Methodology Overview



2. Methodology Overview

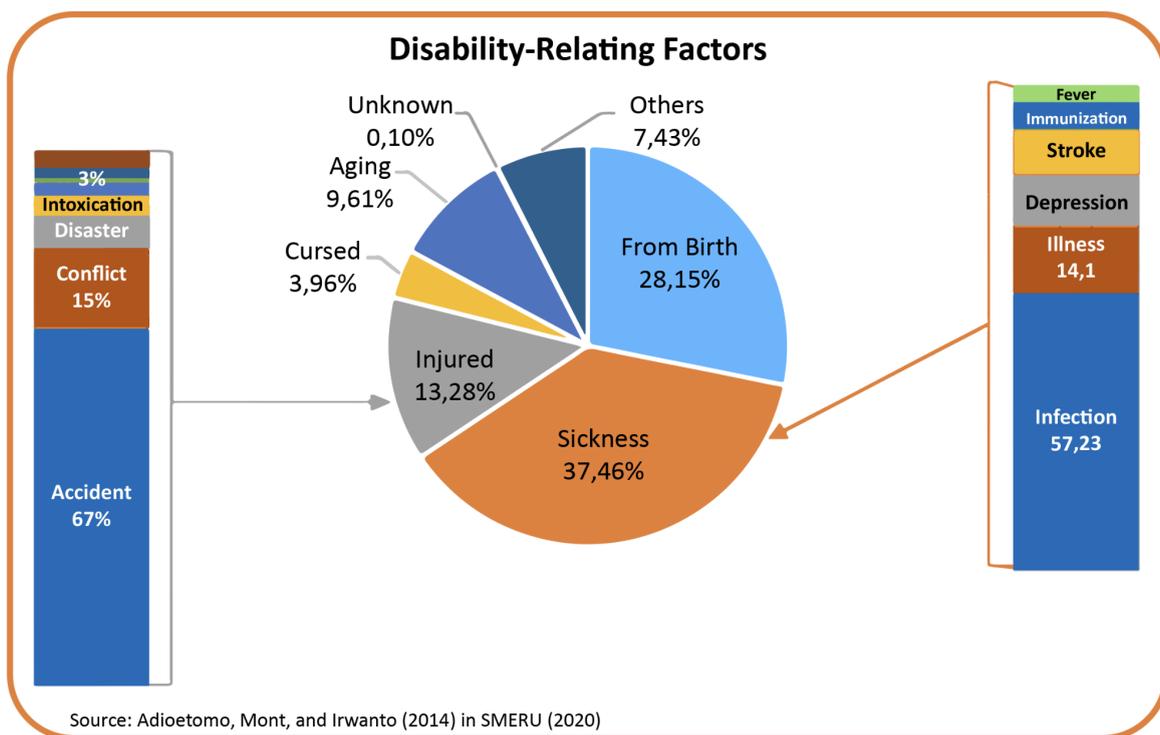
The explanation mentioned above provides a clear and comprehensive understanding of the significance of utilizing a lens of complexity when it comes to comprehending social exclusion. This process involves thoroughly analysing and examining the intricate relationships and connections that exist between various components within a complex system. In order to fully grasp the concept of social exclusion, it is essential to take into consideration the macro perspective, which involves studying and evaluating national regulations, institutions, and policy frameworks that are specifically designed to cater to the needs and rights

of persons with disabilities (referred to as PWDs). By doing so, we can gain a holistic overview of the overall structural landscape that directly influences the well-being and fundamental rights of PWDs. The macro analysis conducted in this study report is based on a strategic evaluation of secondary data, which includes relevant documents and reports, as well as in-depth interviews with key stakeholders at both the national and regional levels. This comprehensive approach ensures that all aspects and dimensions are thoroughly examined and taken into consideration.



Moving forward, the subsequent section of this study report focuses on a micro-level analysis, which aims to provide a detailed understanding of the specific context in which social exclusion is experienced by persons with disabilities in disadvantaged areas. Based on a matrix that considers various factors from the above-mentioned structural parameters in order to understand the position of PWDs in the system landscape, two locations were selected for contextual assessment: West Sumba-NTT and Jayawijaya-Papua. These two areas are considered disadvantaged regions in eastern Indonesia, with low levels in the happiness index, human development index, and gender development index.

Conversely, they have high levels in the poverty index, disability poverty index, and percentage of older population. Besides these similarities, each region possesses its own unique characteristics. Jayawijaya Regency, for instance, is situated in the highlands, has a dense population, a low level of human security, and the lowest level of democracy index. On the other hand, West Sumba Regency has its own distinctive attributes. In addition to indigenous communities with a closed social structure (including indigenous slavery), the population in general has limited access to the internet, and there are several coastal areas in the region that have a low level of environmental security.



Distinguishing itself from the macro analysis, which takes a top-down approach, the micro analysis delves deeper into the systems and processes from an emic perspective. This is achieved

through active immersion and participatory sessions with the affected community. By directly engaging with the community, we can gain valuable insights and perspectives that would otherwise be

overlooked. The importance of conducting a micro analysis in the form of contextual assessment cannot be overstated. This plays a crucial role in understanding social exclusion and inclusion as these concepts are highly dependent on the specific context in which they occur. As highlighted in the UN/DESA Working Papers (2015), the understanding and interpretation of social inclusion varies greatly across different contexts. In fact, various synonymous terms are used to describe social inclusion, such as solidarity, cohesion, social capital, and integration.

However, it is crucial to recognize that the underlying concepts of belonging, membership, and citizenship that are associated with these terms are heavily influenced by the historical and cultural aspects of specific geographical locations. It is important to acknowledge that place-specific ideas and beliefs are deeply ingrained within institutions. These ideas not only shape individual choices and behaviours but also contribute to the formation of social divisions and collective identities. Therefore, it is essential to consider the historical and cultural context when analysing and understanding social exclusion and inclusion. By doing so, we can develop a more comprehensive and nuanced understanding of these concepts and work towards creating inclusive societies that cater to the needs and rights of all individuals, including persons with disabilities.

Ground-Truthing with Immersion Method

Human-centered development possesses the ability to cultivate and encourage dynamic and significant involvement of the community in various development endeavors. This particular approach considers the intricate and diverse array of

cultural principles and the wide-ranging knowledge systems that are present within society. In the existing framework of international and national development tendencies, community participation is widely acknowledged as an essential constituent of the comprehensive development procedure. The technique of participation aims to actively engage the community in the process of societal transformation and progress, and it has garnered substantial traction and popularity over the recent years.

Chambers (2017) provides a comprehensive description of a multitude of participation methods that have emerged over time, each with its own unique characteristics and applications. These methods include immersions, which allow individuals to deeply immerse themselves in a particular community or context, popular theater, which utilizes the power of performance to engage and inspire audiences, the Positive Deviance Initiative (PDI), which seeks to identify and amplify positive deviant behaviors and practices, Participatory Rural Appraisal (PRA), which enables communities to collectively assess their own strengths and weaknesses in a participatory manner, the Most Significant Change (MSC) technique, which involves the systematic collection and analysis of stories of change, Participatory Poverty Assessments (PPAs), which aim to comprehensively understand the dynamics and dimensions of poverty through participatory means, Participatory Learning and Action (PLA), which combines learning and action in a participatory and collaborative manner, community-based development and community-driven development, which emphasize the active involvement and ownership of local communities in development processes, the Reality Check Approach (RCA), which involves the use of

reality checks and performance assessment to inform and guide development initiatives, transformative storytelling, which employs storytelling as a means of fostering empathy, understanding, and social change, the PIALA (Participatory Impact and Learning

Approach), which focuses on generating and capturing participatory insights and learning, and many more. The emergence and diversity of these various participation methods speak to the ever evolving and dynamic nature of community engagement in development efforts.

Key Principles of Immersion Research



Emic; using insiders' perspectives in understanding & interpreting



Unlearn; humble with our understanding and suspending what we think we know



Flexibility; adjusting with the comfort & safety of the people we immerse with



Reflexivity; actively acknowledging & challenging own bias to genuinely listen & empathize with those we immerse with



Contextual; understanding the uniqueness of each context in depth



Complexity; exploring the linkages, networks and pattern of relations of various elements



Multiple realities; recognizing the diversity in a context

UNDP and BIT (2023)

The fieldwork of this study employs immersion method, which essentially means deep mental involvement and is done by opening oneself to understand and feel the in-depth context by applying experiential learning and informal conversations. Immersion is utilized as a method to understand society's perspective in order to develop evidence-based policies. Some scientists classify immersion as ground-truthing, which involves making efforts to connect with the social realities in the field (Birch et.al., 2007). This dynamic and engaged participant observation sets itself apart from the mere acquisition of data or information. For instance, instead of

simply receiving facts and figures about the challenges faced by communities in accessing clean water through public toilets (referred to as MCK), we have the opportunity to engage in meaningful conversations and actively listen to the perspectives of local individuals. By immersing ourselves in the MCK environment and experiencing it as local residents do, or even utilizing the MCK facilities firsthand, we acquire direct experiences and impressions that become ingrained in our minds. When combined with reflective skills during the immersion learning process, this approach grants us valuable insights into the difficulties surrounding access to MCK facilities

(“how”) and the underlying reasons for these challenges (“why”). Thus, immersion holds immense potential for transformative development as it unlocks unforeseen discoveries and revelations (Chambers, 2017).

The immersion which was complemented by participatory sessions conducted by the UN community volunteers in 4 households of persons with disabilities in West Sumba and Jayawijaya. The UN community volunteers talk to various parties, including family, friends, neighbors, employers, and co-workers of persons with disabilities, churches, customs, village and district governments, pig farmers and sellers at markets, service providers (teachers and health workers), and youth. Immersive research looks at the distribution of relationships that make a system robust. The type of data produced through immersion illustrates important relationships between many parts of a system.

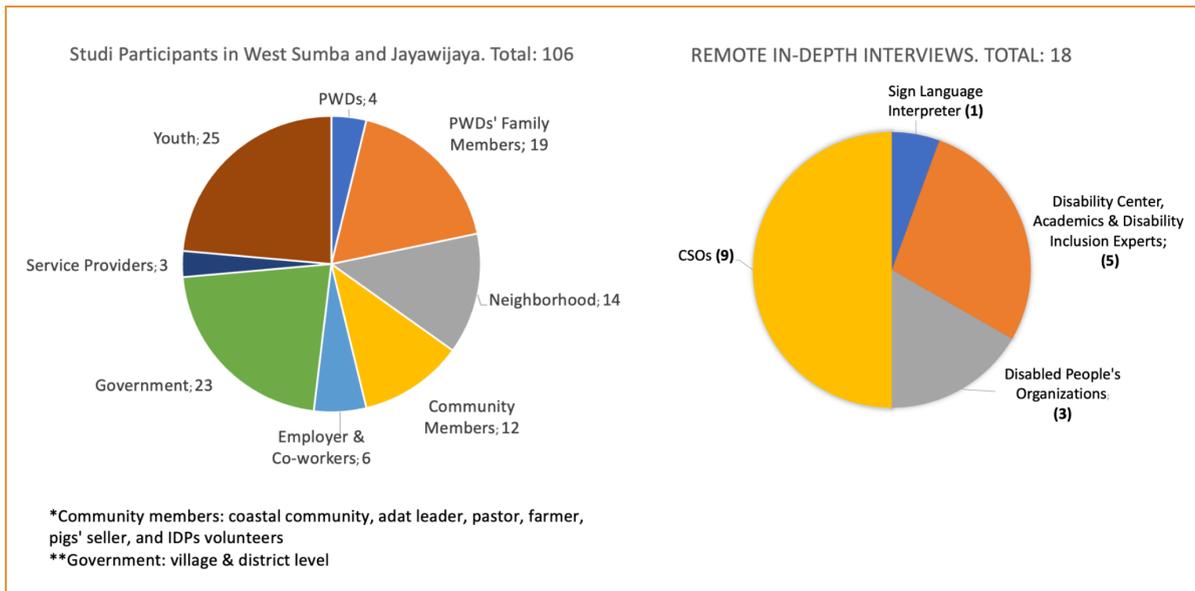
For example, to understand a family, one must understand not only the family members, but also the relationships between them. This is referred to as warm data in the form of information about the relationships that connect the elements of a complex system.

Warm Data, which is transcontextual information, captures qualitative dynamics and offers another dimension of understanding to what is learned through quantitative data, (cold data). Warm Data is used to better understand and improve responses to issues situated within relational dynamics².

The implementation of immersion follows the Do No Harm Approach, which prioritizes the safety and wellbeing of the individuals we engage with. This approach is based on trust and respect, fostering strong relationships.



² <https://warmdatalab.net/warm-data>



The involvement of UN community volunteers in the regions of West Sumba and Jayawijaya consists of a thorough and immersive process utilizing a variety of participatory tools. Prior to engaging in the field, community volunteers undergo immersion training, where they are briefed on the necessary skills for immersion. These skills include deep listening, unlearning, addressing bias and assumptions, empathy, reflective practice, ethnography, and systems thinking.

Additionally, community volunteers are equipped with research tools in the form of Areas of Conversation (AoC), which serve as a guide for informal discussions and participatory visuals. As field research utilizes mixed methods, community volunteers also conduct in-depth interviews and participatory sessions with various stakeholders in the system, including government officials at the village and regional levels, youth, religious and traditional leaders, as well as healthcare workers and educators.



The Research Cycle



These volunteers were actively engaging with persons with disabilities and their families. The objective of this engagement is to gain a deep understanding of the unique challenges and experiences faced by these individuals and their families, with the intention of developing effective strategies and solutions to meet their specific needs. By immersing themselves in the lives of these individuals and families, the volunteers are able to acquire valuable insights and perspectives that will inform the development and implementation of inclusive and empowering initiatives. This hands-on approach enables the volunteers to establish authentic connections and build trust within the community, which is vital

for the success of any intervention or support provided.

Through this collaborative and participatory process, the UN community volunteers strive to foster a more inclusive and equitable society, where the rights and well-being of persons with disabilities are fully respected and upheld. This initiative not only benefits the individuals and families directly involved, but also contributes to the overall advancement of disability rights and social inclusion on a broader scale.



The United Nations community volunteers are conducting immersion activities in the regions of West Sumba and Jayawijaya, with the genuine intention of gaining a deeper understanding of the perspectives and experiences of individuals who are confronted with disabilities, as well as their beloved families. These dedicated volunteers have been equipped with a diverse array of interactive and inclusive tools that are specifically tailored to actively engage and foster the participation of all individuals involved in this process.

The dedication and commitment demonstrated by these volunteers exemplify the UN's dedication to promoting and safeguarding the rights of all individuals, irrespective of their abilities or disabilities. By actively engaging with persons with disabilities and their families, the volunteers are actively contributing to the achievement of the Sustainable Development Goals, particularly Goal 10, which aims to reduce inequality within and among countries. Through their efforts, these volunteers are paving the way for a more inclusive and equal society, where every individual has an equal opportunity to thrive and contribute to the improvement of their communities. The UN community volunteers embody the spirit of volunteerism, selflessness, and compassion, and their contributions are of immense value in promoting social justice and equality for all. Their work in West Sumba and Jayawijaya serves as an

outstanding example of the power of community engagement and the transformative potential of inclusive and participatory approaches.

The UN community volunteers are at the forefront of this groundbreaking initiative, and their dedication and expertise are instrumental in driving positive change and enhancing the lives of persons with disabilities and their families. The immersion activities undertaken by the UN community volunteers are a testament to the UN's commitment to leave no one behind and ensure that every individual has the opportunity to lead a life of dignity and empowerment. Through their hands-on engagement and utilization of participatory tools, these volunteers are making a tangible impact in the lives of persons with disabilities and their families, and their efforts are deserving of the utmost recognition and appreciation.

CHAPTER 3

Findings

The Complexity of the Left Behind PWDs



3. Findings: The Complexity of the Left Behind PWDs

3.1. What's Missing from the Structural Landscape

Disability Paradigm and Mindset

The analysis at the macro level of the structural landscape reveals a complex network of connections that exist between different factors, each of which plays a significant role in shaping the experiences and opportunities available to persons with disabilities within the system. By examining these connections, we can gain a deeper understanding of how they affect the realization of basic rights and the overall welfare of persons with disabilities. It is evident that these connections are crucial in determining the level of support and inclusivity that persons with disabilities receive in society. Failing to acknowledge and address these connections can have profound consequences for the lives and well-being of persons with disabilities.

The examination of the macro-level analysis of the structural landscape uncovers a complex web of connections between mindset, social stigma, the prevailing disability paradigm, governance systems that do not prioritize the needs of persons with disabilities, and the availability of comprehensive data on this particular population within the system. These interconnections, which emerge from this analysis, play a crucial role in

shaping the extent to which fundamental rights are fulfilled and the overall well-being of persons with disabilities is enhanced. The intricate nature of these interrelationships necessitates a deep understanding of the underlying dynamics and their implications for policymaking and intervention strategies. The mindset of individuals, influenced by societal attitudes and beliefs, can have a profound impact on how disabilities are perceived and the subsequent treatment of persons with disabilities. Social stigma, a product of deeply ingrained stereotypes, prejudices, and discriminatory practices, further exacerbates the challenges faced by persons with disabilities. This stigma can manifest in various forms, including exclusion, marginalization, and limited access to opportunities and resources.



“My father is my superhero”

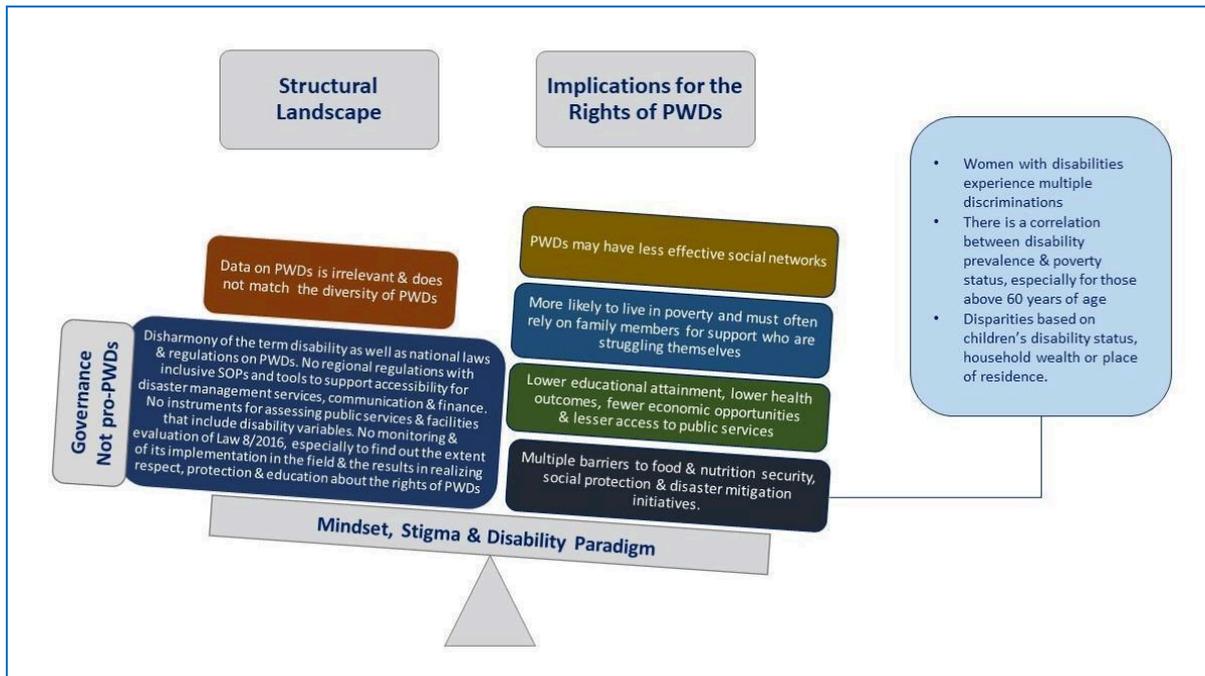
“I have been afflicted with polio since I was just 6 months old. The extended family, believing that my disability would bring misfortune and shame to our name, put immense pressure on my parents. This pressure was especially intense as I am a woman. The family urged my parents to either send me to an orphanage or place me with a childless couple. However, my parents made the bold decision to move to the city in order to escape the suffocating influence of the extended family. They also hoped that this move would provide me with better access to therapy and medication. Despite facing rejection from a regular school, my father insisted on carrying me and accompanying me to school every day. He wanted to ensure that I felt comfortable and supported in my studies. His unwavering belief in me always filled me with enthusiasm and confidence. Even after his passing, my father's support continued to be a driving force in my education. He believed that education was essential for my future independence. I owe who I am today to my father's unwavering support.”

SB, disability activist-NTT, in-depth interview (2023)

Moreover, the prevailing disability paradigm, which shapes societal

perceptions and responses to disabilities, can either enable or hinder the inclusion and empowerment of persons with disabilities. The disability paradigm can be influenced by multiple factors, including cultural, historical, and socio-economic contexts. Inadequate governance systems, characterized by a lack of prioritization of the needs of persons with disabilities, further compound the challenges faced by this population. Such systems may fail to allocate sufficient resources, implement effective policies, and ensure the enforcement of disability rights. Additionally, the availability of comprehensive data on persons with disabilities within the system is critical for understanding their needs, assessing the impact of policies and interventions, and advocating for their rights. The lack of reliable and comprehensive data can impede evidence-based decision-making and hinder efforts to address the specific needs and concerns of persons with disabilities.

Considering these interrelationships, it becomes imperative to adopt a holistic and multi-dimensional approach to disability inclusion and well-being. This approach should encompass policy reforms, awareness campaigns, capacity-building initiatives, and the promotion of inclusive practices across all sectors of society. By addressing the interconnections between mindset, social stigma, the prevailing disability paradigm, governance systems, and data availability, it is possible to foster a more inclusive and equitable society for persons with disabilities.



The term "Persons with Disabilities" as mentioned in Law Number 8/2016 concerning Persons with Disabilities refers to individuals who have physical, intellectual, mental, and/or sensory limitations for a prolonged period. These individuals, when interacting with their environment, face obstacles and difficulties that prevent them from fully and effectively participating alongside their fellow citizens based on equal rights. This legal definition of persons with disabilities, which shifts the perspective from "impairment" to "disability," is in line with the principles stated in the Convention on the Rights of Persons with Disabilities (CRPD). The challenges

experienced by persons with disabilities are not solely a result of their physical and mental conditions, but rather stem from an environment that lacks support and accessibility. This legal definition of persons with disabilities has incorporated the principles of the Convention on the Rights of Persons with Disabilities (CRPD), particularly Article 1 paragraph 2 of the CRPD, which states that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, when faced with various barriers, may impede their full and effective participation in society on an equal basis with others."

“Penyandang cacat”	“Penyandang disabilitas”
‘Impairment’: disabled persons as those having physical and/or mental disorder, which can impair them or become obstacles and barriers consisting of the physically handicapped, the mentally handicapped and the physically and mentally handicapped.	‘Difficulties in functioning’: persons with physical, mental, intellectual or sensory limitations for long periods, who are challenged in interacting with the environment and addressing others, thus preventing them from fully engaging in their guaranteed equal rights.
Charity-based approach	Right-based approach
Focus on PWDs	Focus on PWDs and the provision and maintenance of physical environment to support accessibility of PWDs

The transformation from the paradigm of "impairment" to "disability" has not been fully realized. The usage of the term "penyandang cacat" to refer to persons with disabilities still persists. An example of this can be found in the Omnibus Law on Job Creation (Undang Undang Cipta Kerja)³. This particular usage serves as an indication that lawmakers lack an understanding and neglect the importance of respecting, protecting, and fulfilling the rights of persons with disabilities (PSHK 2020). Article 168 of the Omnibus Law on Job Creation utilizes the phrase "physical and mental health" as a prerequisite for obtaining employment.

³ Omnibus Law on Job Creation (Indonesian: UU Cipta Kerja), officially Law Number 11/2020 on Job Creation (Undang-Undang Nomor 11 Tahun 2020 Tentang Cipta Kerja, or UU 11/2020), is a bill that was passed on 5 October 2020 by Indonesia's People's Representative Council (DPR), with the aim of creating jobs and raising foreign and domestic investment by reducing regulatory requirements for business permits and land acquisition processes.

This discriminatory approach marginalizes people with disabilities as it still considers disability as an illness, encompassing both physical and mental aspects.

The biomedical model adheres to a linear perspective that views impairment as an internal issue within the individual, failing to acknowledge the complexities of social inclusion. When disability is perceived solely as an impairment or limitation, statistical data merely focuses on quantifying the number of persons with disabilities, disregarding the crucial aspect of ensuring their access to education, infrastructure, transportation, job opportunities, healthcare services, legal assistance, and political engagement. Up until this point, disability statistics remain inadequate, as the collected data fails to provide comprehensive and meaningful information about the needs, capabilities, and overall well-being of persons with disabilities (UNCT 2021).

In certain instances, persons with disabilities can only exercise their fundamental rights, such as the right to decent work, mobility, and education, if they fulfill specific administrative requirements, namely obtaining a disability certificate from a hospital doctor or health center doctor. This administrative prerequisite follows a biomedical approach that perceives disability as a medical condition or disorder, one that necessitates examination by a medical professional. For instance, these requirements are obligatory for persons with disabilities when applying for educational scholarships from the Ministry of Education, acquiring driving licenses, pursuing civil servant positions, and fulfilling administrative obligations for air travel.

Information pertaining to disability status can serve as a gateway to affirmative action when it comes to upholding the rights of persons with disabilities. However, the current certification approach adopts an "impairment" framework that primarily focuses on physical condition rather than the overarching rights of people with disabilities. Consequently, the disability certificate required for air travel is often accompanied by a statement placing the full burden of travel risks on PWDs. Unfortunately, in many instances, these administrative requirements not only fail to comprehend the needs of people with disabilities but also unjustly deprive them of their rights. This is due to the fact that disability status is utilized as a discriminatory criterion, leading to instances such as denying a driver's license to a deaf individual or refusing to employ a blind person in a civil servant position. Remarkably, this occurs despite the State Civil Apparatus (ASN) Bill

mandating a 2% quota for the employment of PWDs within the total ASN. Thus, there is a pressing need to establish human rights guarantees that transcend the scope of administrative nature.

Disability, which refers to a condition that impacts individuals' physical or mental capabilities, is not confined solely to the realm of legislation, but rather extends its influence to encompass various aspects of societal construction. Apart from the legal framework that addresses the rights and protections of PWDs, it is important to recognize that the perception of charity towards this group persists in multiple public domains and permeates everyday life. However, the understanding and interpretation of disability within public spaces have yet to fully embrace a rights-based approach and a comprehensive perspective that takes into account the entirety of the ecosystem in which persons with disabilities exist.

Acknowledging the fundamental rights inherent to every individual becomes crucial when considering the existence of structural barriers that contribute to the prevailing inequality observed in society. It is disconcerting to observe that the presentation of what is often referred to as "inspiration porn" remains prevalent in public spaces, particularly exemplified by television shows that showcase persons with disabilities engaging in extraordinary achievements. This exploitative portrayal tends to evoke feelings of pity rather than addressing the genuine issues surrounding public accessibility for people with disabilities.

The perpetuation of the charity mindset, which has been deeply ingrained in society long before the enactment of Law Number 8 of 2016, necessitates ongoing

efforts aimed at transforming this perspective within civil society. It is crucial to involve persons with disabilities themselves in these efforts, as they are an integral part of the process of bringing

about change and ensuring the realization of equal rights and opportunities for all individuals, regardless of their abilities.

The right to live independently and with dignity

“I am constantly working to support my colleagues with disabilities in altering our perspective. After dedicating so much time to charity work, fellow individuals with disabilities have come to believe that we can only receive assistance in that manner. We have not considered the possibility of working because every month we receive aid, which is referred to as diakonia in the church, specifically for people with disabilities. These circumstances hinder our ability to be creative and independent. It is necessary for us to transform our mindset so that we can have the same opportunities to actively manifest our potential and not solely rely on charity. The mindset of our supporters, including our families, must also undergo a transformation in order to fully support our pursuit of independence.”

SB, disability activist - NTT, in-depth interview (2023)

Despite the prevailing social model, which views disability as an oppressive experience within society for individuals with impairments, it is imperative that society undergoes a transformative change in order to accommodate and integrate persons with disabilities. The human rights model, on the other hand, necessitates the realization and fulfillment of human rights as the ultimate solution to prevent individuals with physical, mental, or sensory limitations from encountering social exclusion, as advocated by SMERU in 2020. The Convention on The Rights of Persons with Disabilities (CRPD) in 2007 serves as a crucial instrument that guarantees social inclusion for persons with disabilities. In this particular context, inclusivity encompasses creating conditions that facilitate meaningful participation and

active involvement of all individuals, irrespective of any form of discrimination.

HRBAD in PWDs Data Ecosystem

In the month of June in the year 2019, the act of issuing Presidential Regulation No. 39 of 2019 pertaining to One Data Indonesia by the President signifies a strong call to action for the synchronization of data that is acquired by each individual ministry and agency, with the ultimate goal of enhancing its accuracy, timeliness, integration, transparency, accessibility, and shareability. This particular policy serves as a tangible embodiment of the government's unwavering commitment to establishing a comprehensive open government framework that spans across all levels, ranging from the local to the

national level. Nevertheless, it is crucial to acknowledge that despite this commendable effort, there still exist numerous obstacles that persist in effectively implementing the One Data Policy or Satu Data Indonesia. For instance, one significant challenge lies in the integration of thousands of applications, which poses a formidable obstacle to overcome. Additionally, it is

important to note that the existing level of expertise in relation to data within the country of Indonesia remains inadequate, further exacerbating the difficulties encountered in this endeavor. The government has explicitly highlighted that the most persistent hurdle lies in the presence of sectoral egos, whereby various agencies are hesitant and unwilling to share their valuable data.

Six principles of Human Rights Based Approach to Data (HRBAD) according to UN Office of the High Commissioner for Human Rights (2018):

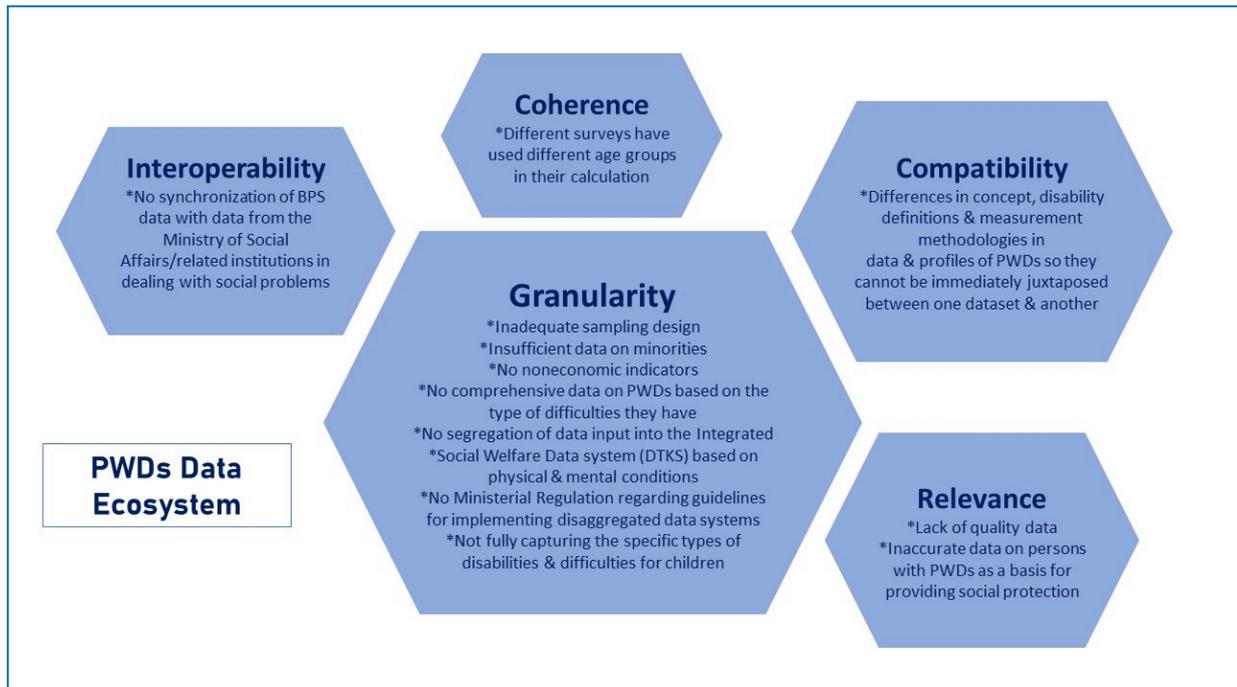
1. **Participation:** participation of relevant population groups in data collection exercises, including planning, data collection, dissemination, and analysis of data
2. **Data disaggregation:** allows data users to compare population groups, and to understand the situations of specific groups
3. **Self-identification:** for the purposes of data collection, populations of interest should be self-defining. Individuals should have the option to disclose, or withhold, information about their personal characteristics
4. **Transparency:** data collectors should provide clear, openly accessible information about their operations, including research design and data collection methodology. Data collected by State agencies should be openly accessible to the public
5. **Privacy:** data disclosed to data collectors should be protected and kept private, and confidentiality of individuals' responses and personal information should be maintained
6. **Accountability:** data collectors are accountable for upholding human rights in their operations, and data should be used to hold States and other actors to account on human rights issues.

Without a doubt, one of the notable obstacles hindering the achievement of a successful one data policy is the lack of interoperability. However, upon conducting an in-depth analysis of policy and programs, it becomes evident that there are numerous other obstacles that significantly impact the data ecosystem of persons with disabilities. These obstacles include issues of coherence, compatibility, granularity, and relevance. Apart from the

pressing issue of coordination between different government agencies, it is essential to acknowledge that the absence of a disability paradigm, encompassing factors such as awareness, knowledge, and skills, as well as the absence of systems thinking, are underlying factors that contribute to the creation of various obstacles within the data ecosystem. This illustrates the intricate and interconnected connections that exist between mindset,

stigma, and the different types of knowledge products and decision-making processes. The complicated dynamics at play within these areas can be observed through the lens of dialectics. The understanding and grasp of individuals when it comes to PWDs have a significant

influence on the types of data that are gathered and the policies that are created. It is precisely this understanding that shapes the direction and nature of the knowledge that is produced, as well as the subsequent decision-making processes that are put into action.



The Human Rights Based Approach to Data (HRBAD), which positions people with disabilities as the central figures responsible for holding and managing data, has not yet been put into action within the PWDs data ecosystem. By drawing upon the valuable insights gained from the emergency unit's experience in effectively managing vaccinations for PWDs as part of the extensive efforts to combat the Covid-19 pandemic, it becomes strikingly evident that the crucial cards for One Data for All, encompassing comprehensive information on identification (KTP), are of utmost importance. The emergency unit faced

numerous challenges when it came to accessing integrated data. Specifically, the Ministry of Social Affairs possesses significant data pertaining to disability status, yet it lacks the necessary data regarding vaccine status. On the other hand, the Ministry of Health possesses data regarding vaccine status, but it lacks the essential data regarding disability status.

In order to streamline and facilitate the accessibility of various services for persons with disabilities, the issuance of Regulation Number 2 of 2021 by the Minister of Social Affairs, also known as

the Card for Persons with Disabilities, aims to establish an official identity for these individuals. This official identity plays a vital role in ensuring that the rights of persons with disabilities are fully upheld in accordance with national data. Moreover, the application of the HRBD emphasizes

the need to incorporate the perspectives and experiences of PWDs as the primary data holders. This inclusivity is crucial in order to generate identity-related policies that are not only applicable but also highly relevant to the unique needs and circumstances of persons with disabilities.

“Disability is part of my identity”

“The possession of a Family Card (KK) and an ID card (KTP) is incredibly important in order to fully enjoy the rights that we, as citizens, are entitled to. We must always remember that disability is not just our sole identity, but rather an integral part of who we are, just as much as our role as the head of a family. It is of utmost importance that our Family Card (KK) and Identity Card (KTP) promote inclusiveness by incorporating our disability status, rather than isolating it into separate disability cards. Unfortunately, the current process of obtaining an ID card at the sub-district office excludes individuals with severe disabilities, which is truly disheartening. As Persons with Disabilities, if we are not registered in the government system, we run the risk of losing our basic rights. A truly alarming example of this is the situation in Jayapura, Papua, where over 500 PWDs were not included in the Permanent Voter List (DPT) prior to the 2019 elections, thereby putting their political rights in jeopardy. In contrast to the government's approach, we strive to carry out a thorough and accurate data collection process. It is absolutely essential that the General Election Commission (KPU) actively involves us and carries outdoor-to-door data collection, to truly hear our voices and fully address our needs.”

RN, disability activist, Papua, in-depth interview (2023)

Rights-Based Approach in Social Inclusion Process

A development approach that is rooted in Human Rights places great emphasis on the active participation of individuals as key participants and owners of the development process. This all-encompassing approach highlights the significance of integration, cooperation, and collaboration among various stakeholders in order to address disparities in development programs. In

the Indonesian context, inclusivity is incorporated structurally through different expressions in policy, such as the utilization of the term "special". As highlighted by Bappenas (2021), the term "special needs" does not exclusively pertain to persons with disabilities, but also encompasses the elderly (in the realm of transportation) or students who possess unique talents (in the field of education). In the National Education System Law, persons with disabilities are

outlined in Article 32, paragraph (1), which states that "Special education is intended for students who encounter difficulties in the learning process due to physical, emotional, mental, or social disabilities, and/or exhibit exceptional intellectual and talents."

Several good programming practices as implications of a Human Rights Based Approach (HRBA) to development:

- People are recognized as key actors in their own development, rather than passive recipients of commodities and services
- Participation is both a means and a goal
- Strategies are empowering, not disempowering
- Both outcomes and processes are monitored and evaluated
- Analysis includes all stakeholders
- Programmes focus on marginalized, disadvantaged, and excluded groups
- The development process is locally owned
- Programmes aim to reduce disparity
- Both top-down and bottom-up approaches are used in synergy
- Situation analysis is used to identify immediate, underlying, and basic causes of development problems
- Measurable goals and targets are important in programming
- Strategic partnerships are developed and sustained

UNSDG (2003)

The term "special needs" is mentioned in the Circular Letter issued by the Director General of Primary and Secondary Education, numbered 380/C C6/MN/2003 and dated January 20, 2003, which addresses Inclusive Education. However, rather than promoting inclusivity, the term "special" perpetuates a segregating and exclusive approach towards individuals who are deemed to have special needs, including those with disabilities. Exclusivity stands in direct opposition to inclusivity and does not align with the principle of equality, as expressed by a disability advocate who stated, "We do not desire special treatment because that would only isolate us. For instance, persons with disability-only ATMs should not be created. Rather, ATMs should be accessible to anyone."

The choice of the word "special" mentioned earlier fails to adequately acknowledge the importance of a rights-based approach and the fundamental principles of social inclusion. Social inclusion can be defined as the deliberate action of accommodating and considering the perspectives and viewpoints of individuals within a social setting. This includes understanding and acknowledging the wide range of needs, perspectives, and related factors that exist within the setting. By ensuring adequate accessibility and creating an environment that fosters meaningful engagement, social inclusion aims to provide equal opportunities for all participants involved.

Social inclusion pertains to the action of accommodating and considering the viewpoint of individuals within a social setting. This encompasses the understanding and acceptance of the various needs, perspectives, and related factors that exist within this setting. Moreover, it involves facilitating

meaningful engagement by ensuring adequate accessibility, thereby ensuring that equal opportunities are provided for all participants within said social setting. The principles of disability inclusion can be broken down into five core tenets that serve as the foundation for fostering a more inclusive society. These principles are diversity, which encompasses the recognition and acceptance of different types of disabilities; accessibility, which emphasizes the importance of ensuring that environments, products, and services are accessible to persons with disabilities; appropriate provision of resources, which involves making the necessary resources available to support persons with disabilities; active participation, which encourages persons with disabilities to actively engage and participate in all aspects of life; and the absence of discrimination, which highlights the importance of treating persons with disabilities fairly and without prejudice.

Understanding the unique circumstances and perspectives of persons with disabilities is crucial in implementing these principles, as it allows for the development of tailored solutions that cater to their specific needs and requirements. Each individual with a disability possesses their own set of conditions and requirements, which must be taken into account when creating inclusive environments and opportunities. For example, the concept of eco-ableism emerged during the prohibition of plastic straws, which unintentionally excluded persons with disabilities who were unable to utilize metal straws due to their unique circumstances and requirements. This highlights the importance of considering the diverse needs and perspectives of persons with disabilities in order to ensure that no one is left behind in the pursuit of social inclusion and equal opportunities.

Acknowledging the wide range of disabilities that exist is crucial in order to effectively implement inclusive infrastructure policies that cater to the diverse needs of persons with disabilities. Disabilities manifest in a multitude of characteristics, presenting unique challenges and requirements for accommodation. Take, for example, visually impaired individuals who face varying degrees of vision loss. Some individuals experience complete blindness, where their visual perception is entirely absent, while others have limited vision, which entails the ability to perceive some visual stimuli to a certain extent. In the context of partial vision loss, a term commonly employed is "low vision", denoting a condition characterized by a decrease in visual acuity coupled with the retention of partial vision capabilities. This condition affects individuals with vision impairments who find it difficult to read a newspaper at a normal distance, even with the aid of corrective eyewear like glasses or contact lenses. Consequently, individuals with visual impairments often necessitate modifications in lighting conditions and/or the enlargement of printed materials to facilitate their reading experience.

Within the category of low vision, there exist two specific subcategories that further differentiate the nature of visual impairments: myopia and hypermetropia. Myopia refers to the inability to clearly perceive distant objects, often colloquially referred to as "farsightedness". On the other hand, hypermetropia refers to the incapacity to see close objects with clarity, also commonly known as "farsightedness". These distinct subcategories of low vision necessitate tailored approaches to knowledge acquisition and accommodation. For individuals who are completely blind, their

reliance on alternative methods of obtaining information becomes paramount. One such method is the utilization of braille, a tactile writing system specifically designed for individuals with visual impairments. Braille can be encountered in two main forms: hand braille and foot braille. Hand braille refers to the embossed dots on paper or other surfaces that allow visually impaired individuals to read through touch. Foot braille, on the other hand, involves the attachment of braille labels to sticks that are used for tactile navigation on the ground. These sticks, known as guide blocks and warning blocks, enable individuals with visual impairments to navigate their surroundings with greater ease and safety.

Conversely, individuals with low vision, who possess some residual visual capabilities, may benefit from the presence of colored guide blocks. These colored guide blocks, such as those in vibrant hues of yellow, serve as visual cues that aid individuals with low vision in navigating their environment. It is important to note that individuals with low vision who do not heavily rely on tactile feedback or utilize a cane extensively often depend on light and color as crucial visual aids. Therefore, the use of bright and distinct colors becomes particularly significant in facilitating their orientation and mobility. The diverse nature of disabilities necessitates a nuanced understanding and recognition in order to implement inclusive infrastructure policies that effectively cater to the needs of persons with disabilities.

By acknowledging the extensive array of characteristics displayed by disabilities, including visual impairments in specific contexts, it becomes evident that distinct subcategories of visual impairment necessitate tailored approaches for the acquisition of knowledge and provision of accommodations. Whether it entails the utilization of braille or the integration of guide blocks of different colors, it is of paramount importance to furnish the essential tools and adaptations that facilitate the integration and empowerment of persons with disabilities into society. Allocating diverse spaces for each individual to process this knowledge represents one of the fundamental pillars for establishing inclusive and meaningful participation.

Ableism compounds the negation of diversity in the processing of knowledge. Ableism, as a parameter, constitutes a form of discrimination and prejudice directed towards persons with disabilities. It embodies a negative mindset that excludes and marginalizes people with disabilities, thereby perpetuating the notion that they are inferior or less capable than individuals without disabilities. Ableism is deeply rooted in stereotypes and stigmas associated with disability and can result in social exclusion, limited access to opportunities, and systematic discrimination across various domains of life. Developing an understanding of ableism is crucial in promoting inclusivity and ensuring equal rights for people with disabilities.

Indicators of ableism that eliminate opportunities

“There was a remarkable prospective student who possesses an intellectual disability and a learning disability. It fills my heart with joy to share that she achieved a remarkable feat by securing the 3rd place in one of the special Olympics for individuals with intellectual disabilities in Germany. Upon her return, she was presented with a university entrance interview, a momentous opportunity indeed. However, it is disheartening to witness the lack of understanding among many individuals regarding the intricacies of intellectual disabilities, particularly the existence of two distinct age systems. While her biological age stands at 18 years, her mental age remains that of a tender child, ranging from 9 to 10 years. During a crucial meeting with campus officials, to my dismay, she was unjustly declared as having failed the interview. This deeply unfair decision was made solely because she chose to remain silent when asked to read, leading to the assumption that she was incapable of doing so. Yet, the truth is that she possesses the ability to read, albeit at a slower pace, but initiating conversation with new acquaintances proves to be quite challenging for her. It is with great disappointment that I acknowledge the decision to deem her unsuccessful was a prime example of ableism, as it employed standards that fail to account for the unique circumstances faced by individuals with intellectual disabilities.”

IS, disability center, in-depth interview (2023)

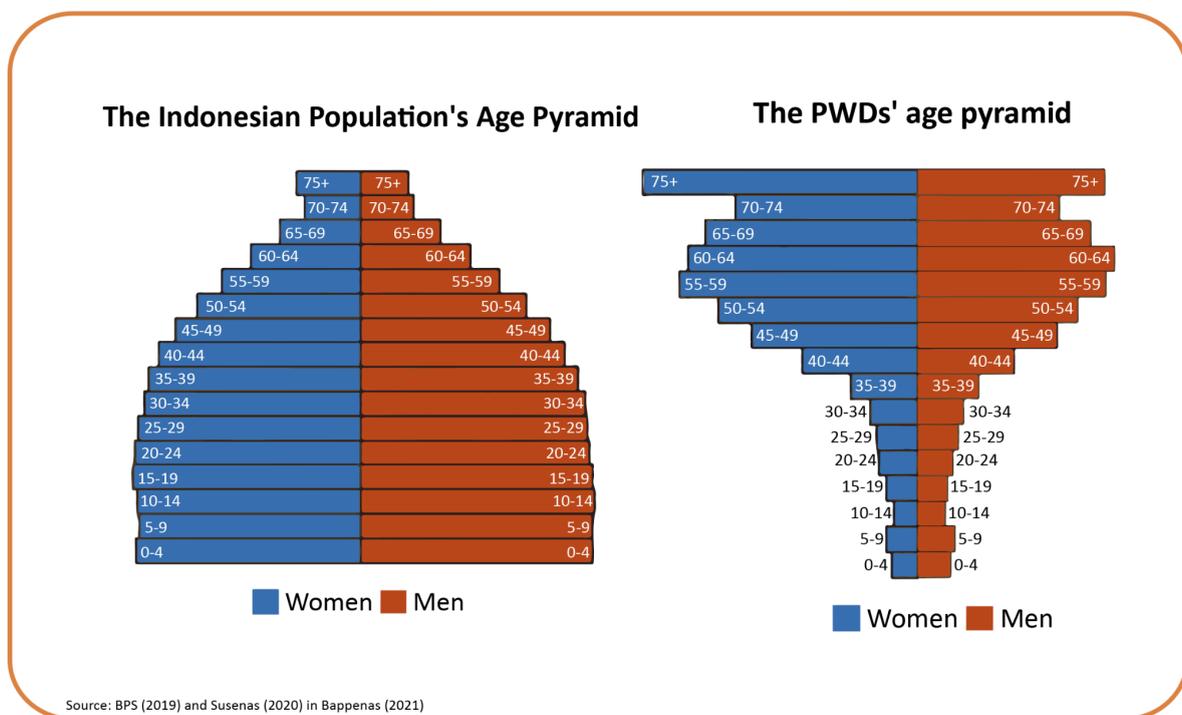
Even though the term "special needs" is employed within the national policy framework, it fails to adequately address diversity, including the provision of essential necessities. This deficiency becomes evident in the absence of social safeguards specifically tailored to persons with disabilities (MOST-UNESCO BRIN, 2022), thereby perpetuating a state of structural exclusion. In many circumstances, this exclusionary framework is further exacerbated by additional forms of marginalization, specifically stigma and discrimination, which create multiple layers of exclusion and heighten the vulnerability of certain population segments. The lack of granularity in addressing diversity further hampers the achievement of inclusive protection, resulting instead in the reinforcement of horizontal disparities.

Furthermore, the absence of regulations that comprehensively safeguard the rights of persons with disabilities in an inclusive manner compounds the issue of structural exclusion. For instance, the National Commission on Violence Against Women (2019) elucidates that the selection criteria for workers and civil servants, pertaining to their physical and mental well-being, fail to guarantee the social inclusion of persons with disabilities. Nevertheless, individuals with psychosocial disabilities face an additional layer of exclusion.

The implementation of affirmative quotas for individuals with persons with disabilities, encompassing 2% for Civil Servants and State-Owned Enterprises, and 1% in the private sector, does not ensure inclusivity for individuals with

psychosocial disabilities. Additionally, there is no guarantee that the exploitation of individuals with psychosocial disabilities, such as unpaid or inadequately remunerated employment, will be eradicated. Beyond the realm of public spaces and workplaces, women with psychosocial disabilities encounter multiple layers of exclusion within their private spheres. Generally, there persists a stigma that perceives disability as a curse or source of shame, thereby rendering persons with disabilities as asexual beings. Women with speech impairments and intellectual disabilities face an additional

layer of exclusion rooted in discrimination against their sexual and reproductive health rights. Some women with disabilities who experience communication difficulties are at a heightened risk of vulnerability, becoming targets of exploitation, including physical or sexual violence. This intricate intersection of stigma and discrimination underscores the complexities inherent within the context of persons with disabilities, as well as the diverse array of risks experienced within this demographic.



Inclusive Development as a Transformative Force

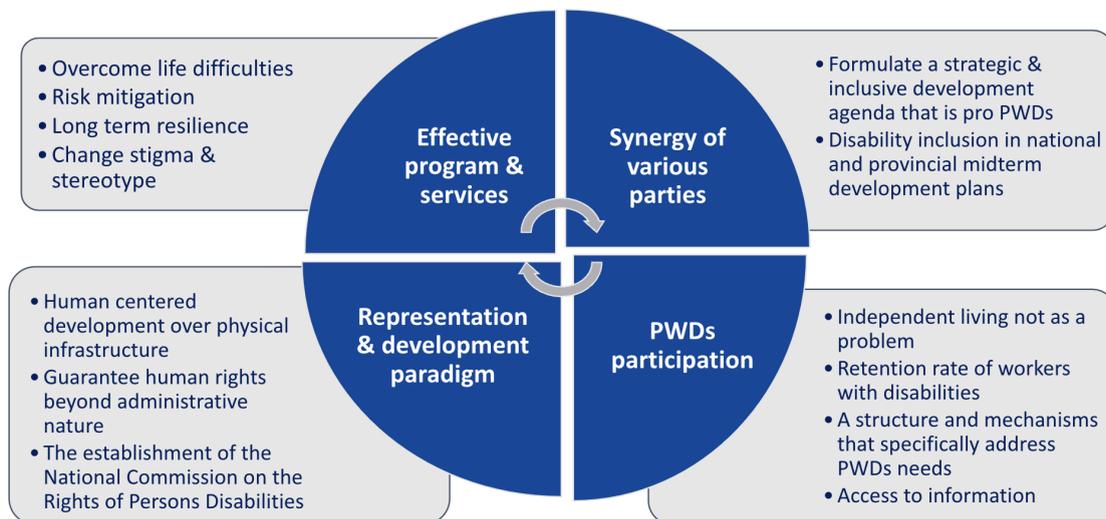
The term disability and its alignment with national legislation concerning persons with disabilities presents a significant lack of harmony. In order to address this issue, the National Research Innovation Agency

(BRIN, 2021) has meticulously identified a range of laws that pertain to persons with disabilities and require a process of harmonization. These laws include Law no. 40 of 2004, Law no. 11/2009, Law no. 13/2011, Law no. 24/2011, Law no. 23 of 2014, Law no. 40 of 2014, Law no. 8/2016, and Law no. 14/2019. It is worth noting

that within these laws and regulations, there are various terms employed to refer to persons with disabilities. For instance, the usage of terms such as "Penyandang Cacat," "Cacat," "Difabel," "Difable," and "Berkebutuhan Khusus" can be observed within Numbers of Regional Regulations, Ministerial Regulations, and Regional Head Regulations (Peraturan Kepala Daerah). Furthermore, Article 29 paragraph (1) of Law No. 25/2009 on Public Services employs the term

"Masyarakat Tertentu," while Article 5 paragraph (3) of Law No.39 /1999 on Human Rights employs the terms "Kelompok Masyarakat Rentan" and "Kelompok Rentan," which encompasses PWDs as outlined in Article 55 of Law No.24/2007 on Disaster Management. It is imperative that these terms are analyzed and addressed in order to establish a unified and cohesive framework within national legislation.

What is missing in the institutional & policy framework on PWDs?



Despite the existence of Law Number 8 of 2016, which provides legal protection for persons with disabilities, there has been a lack of monitoring and evaluation regarding the implementation of this law. This has hindered the understanding of the extent to which the rights of persons with disabilities are being respected, protected, and promoted. The use of terms other than "Persons with Disabilities" in statutory regulations has had a cascading impact, affecting national

policy and its implementation at the regional level. These effects include a lack of clarity in the formulation of statutory regulations, delays in policy implementation, challenges in allocating a development budget that promotes inclusivity, difficulties in gathering disaggregated data, and obstacles in monitoring and evaluating related regulations (Bappenas 2021). The implementation of policies also faces challenges due to the absence of technical

guidance, such as assessment instruments for public services and facilities that consider disability variables. Additionally, there is a lack of regional regulations with inclusive standard operating procedures and supporting tools for accessibility in disaster management, communication, and financial services. Consequently, the capacity to allocate budget for disability inclusion in the government work plan continues to face challenges.

The realization of mainstreaming disability issues in the policy-making process has yet to be achieved. It is important to note that national and provincial midterm development plans currently do not adequately address disability inclusion within thematic development policy and programs, with the exception of social protection and disaster mitigation. In order to enhance the effectiveness of social protection programs, it is crucial for them to be more responsive. Presently, out of the 89 types of Social Protection Programs, only the Smart Indonesia Program (PIP) and the Family Hope Program (PKH) explicitly incorporate people with disabilities as one of the criteria for receiving assistance. However, in order to further promote inclusivity, a Social Protection Budget allocation that specifically targets people with disabilities is required. This implies that people with disabilities should be considered as a separate criterion in the eligibility requirements for receiving assistance, rather than solely focusing on criteria related to poverty. Therefore, persons with disabilities should be considered as one of the main beneficiaries of social protection programs.

Both the public and the development sector are increasingly cognizant that conventional methods of comprehending problems and executing interventions are

incongruous for intricate and rapidly evolving challenges. A Framework for System Transformation has been extensively implemented across both the public and private sectors to yield transformative outcomes⁴. The development process, aimed at accomplishing system transformation, incorporates the principles of Leave No One Behind (LNOB) by addressing inequality and engaging the perspectives and experiences of affected communities. In its report, IPBES (2022) underscores that transformative change can be propelled by synergistic actions from diverse actors, placing sustainability at the forefront of decision-making by redefining the concepts of "development" and "good quality of life".

The same report elucidates that transformative change necessitates inclusive social learning that encompasses diverse forms of knowledge, including the wisdom of indigenous peoples and local communities, while also delineating how disparities among sociodemographic groups (such as different genders and generations) impact decision-making. To expedite transformative change, we must facilitate ethical and equitable knowledge co-production, ensuring the incorporation of the interests and diverse knowledge systems of various stakeholders, including local communities, indigenous peoples, youth, and persons with disabilities⁵.

Inclusive development is concerned with a human development approach that focuses on creating fair opportunities and choices for all people to "be" and "do" the

⁴<https://undp-ric.medium.com/portfolio-approach-es-to-tackle-complex-challenges-notes-on-an-emerging-practice-135b44ed0507>

⁵ IPBES (2022) and International Science Council (2023)

things they want in life⁶. In the capability approach, philosopher Martha Nussbaum posits that in order to attain its utmost potential, human life must encompass various "capabilities" - specifically, genuine prospects that an individual can actualize in their life. This encompasses the capacity to lead a life of substantial value, the ability to employ one's imagination, adequate education to foster a "genuinely human" comprehension of the world and one's position within it, possessing dignity and a sense of equal worth, and the ability to engage in the political realm of their society.

Nussbaum further underscores that a fully realized human life can be assessed in terms of functioning. At its most fundamental level, a capability denotes a genuine possibility of accomplishing or attaining something. The crux of the matter lies in the requirement for this possibility to be real. Capability pertains to the inherent or acquired qualities that empower an individual or entity to execute a specific task or function. It represents the potential to achieve something. Conversely, capacity refers to the utmost amount of work that an individual or entity can undertake within a given period. It embodies the ability to deliver outcomes. Capability pertains to the quality of work produced, whereas capacity pertains to the quantity of work produced. Capacity is gauged in units such as hours, units, or volume, while capability is assessed in terms of skills, knowledge, and aptitude.

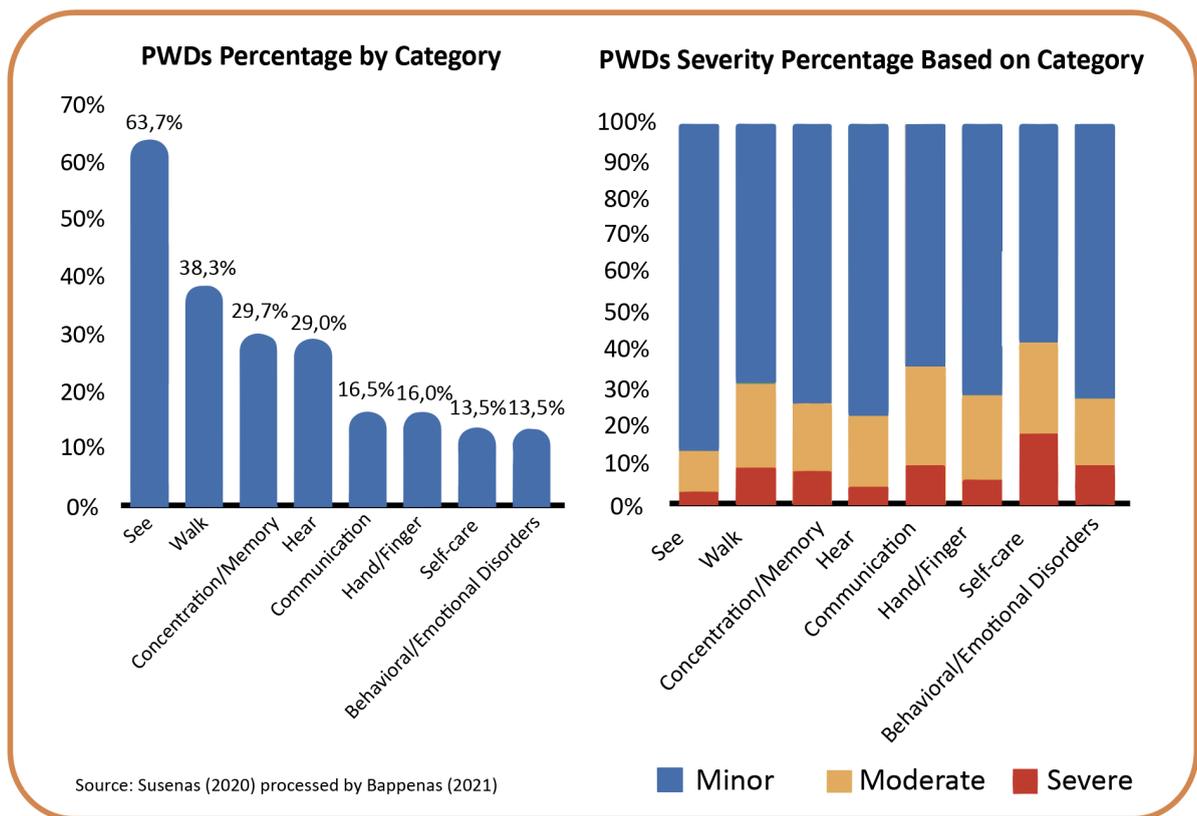
Bappenas (2021) acknowledges that several existing programs and services have not proven effective in reaching all

persons with disabilities in their endeavor to overcome life challenges, mitigate the risks they encounter, and foster long-term resilience, nor have they substantially altered the prevailing stigmatization and stereotypes surrounding people with disabilities. The principle of inclusive development seeks to rectify disparities that arise as a result of power imbalances, limited voice, and diminished influence among individuals/groups (including individuals/groups with disabilities) within the development process. On a macro level, expediting the implementation of inclusive development for persons with disabilities in Indonesia necessitates commencing with the formulation of an inclusive development master plan, followed by large-scale interventions to eradicate the stigmatization of disability groups, and the establishment of the National Commission on Disabilities (abbreviated as KND), which will assume the role of overseeing disability-related matters. In accordance with Article 134 of Law 8/2016, the Government is obliged to establish a National Commission on Disabilities. As outlined in Presidential Decree 69/2020, which was promulgated on 8 June 2020, the Ministry of Social Affairs leads the formation of the National Commission on Disabilities.



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<https://hdr.undp.org/content/what-human-development>



The utilization of inclusive development principles is directed towards enhancing the circumstances of inequality that arise as a result of imbalances in power, voice, and influence amongst individuals/groups (including individuals/groups with disabilities) in the process of development. One of the manifestations of such inequalities is the absence of social protection that is specifically tailored for people with disabilities. In point of fact, the provision of social protection has the capacity to diminish the gap of poverty. Based on TNP2K (2019), Indonesia possesses the means to furnish adequate social protection for persons with disabilities. For instance, the program would encompass more than 860,000 children with severe disabilities (which accounts for approximately 1% of the entirety of children), as well as 1,596,000 adults of working age with

severe disabilities (which constitutes 1% of the working-age population). The disability benefit would precipitate a reduction in the poverty rate across households with a member who has a severe disability by 44%, while concurrently diminishing the poverty gap by 53%.

Meaningful Participation: *"Nothing About Us Without Us"*

The Presidential Decree 59/2017, which addresses the implementation of the Sustainable Development Goals, emphasizes the involvement of persons with disabilities in decision-making processes. This decree is rooted in Global Goal XVI, which highlights the importance of inclusive and representative decision-making at all levels. Furthermore, Government Regulation Number 70 of 2019 stipulates that persons with

disabilities have the right to participate in the planning, implementation, and evaluation of initiatives aimed at respecting and fulfilling their rights. This indicates that persons with disabilities should be included in all processes and decision-making that affect their well-being.

According to the 2020 Global Inclusion and Marginality framework by Bappenas, Indonesia ranks 125 on the inclusivity index, placing it below countries such as the Philippines, Vietnam, Singapore, and Thailand. The inclusivity index provides a comprehensive assessment of inclusive development, focusing on equality in terms of race/ethnicity, religion, gender, and disability. It considers various aspects, including political representation, non-group violence, income inequality, incarceration rates, and immigration and refugee policies. The indicators of inequality that comprise the inclusive development index can be observed through the welfare status of persons with disabilities in Indonesia. These indicators encompass limited educational opportunities, subpar health outcomes, constrained economic prospects, and restricted access to public services. Persons with disabilities are more susceptible to living in poverty and often rely on struggling family members for support.

Moreover, their social networks may be less effective in addressing the multifaceted challenges they encounter, including barriers to food and nutrition security, social protection, and disaster mitigation initiatives. Intersectional variables further illustrate variations in risk among different disability groups. Discrimination against women with disabilities manifests in various forms. Notably, there exists a correlation

between the prevalence of disability and poverty status, particularly among those aged over 60 years. Disparities can also be observed based on child disability status, household wealth, or place of residence.

It is evident that disability inclusion has not yet been incorporated into national and provincial midterm development plans. Out of the 548 regions in Indonesia, a total of 113 or 20.6% have regional regulations pertaining to persons with disabilities. These regulations are spread across 20 provinces, 27 cities, and 66 districts. Nonetheless, it is paramount for affirmative policies to allocate attention to infrastructure and technical instructions for the purpose of effective implementation. It is essential to have a strategic and comprehensive development agenda that gives priority to persons with disabilities. Furthermore, there is a lack of regional regulations pertaining to buildings that adhere to accessible building standards set forth by the Ministry of Public Works and Public Housing. This issue is compounded by the lack of meaningful participation from persons with disabilities, resulting in a misalignment of development efforts and the failure to uphold the rights of persons with disabilities. Achieving accessibility requires a synergistic approach among various stakeholders, and further elaboration on the division of roles, responsibilities, and mandates within governmental agencies is warranted. However, it is important to acknowledge that this specific document is still in the developmental phase.

Organizations catering to persons with disabilities (OPDs) have been positioned as proactive advocates due to the assertion of an activist, who stated, "We must adopt a proactive stance because relying solely on the government will not

enable them to comprehend our experiences." OPDs also engage in self-mobilization endeavors where individuals actively participate by taking independent initiatives to effect change within existing systems. They establish connections with external institutions in

order to access resources and seek technical guidance, while simultaneously maintaining autonomy over resource allocation. These endeavors can also manifest as social movements, thereby instigating social transformation.

More than just a checklist

"As a person with a disability, I was invited by one of the government banks to try a wheelchair ramp that they had built without any understanding of accessibility and related regulations. It turns out the wheelchair ramp they built was too steep and the building was inaccessible. People with disabilities must be involved in the process, not just be the result. Sometimes we participate but people don't ask for our opinion. So, until now every time I go there, I must be helped because the wheelchair ramp is too steep. After that I still have to be helped because when I want to enter the main door there are flowerpots blocking it. This lack of access also applies to all wheelchair users, including the elderly."

SN, disability activist- NTT, in-depth interview (2023)

One of the contributing factors hindering the realization of the rights of persons with disabilities is the insufficient involvement of these individuals in the formulation of relevant policies. The active participation of Organizations of Persons with Disabilities enhances the provision of services. However, a framework and mechanisms specifically addressing the needs of Persons with Disabilities are yet to be developed to facilitate transformative participation, which ultimately results in the empowerment of all stakeholders involved and consequently reshapes the prevailing structures and institutions that perpetuate marginalization and exclusion. It is only through the embodiment of "transformative participation" that those in positions of power stand in solidarity with the less privileged, taking decisive actions and influencing decisions.

If we comprehend it in this manner, participation is not just a mere formality; it is a right that should be actively pursued. Furthermore, it plays a crucial role in enhancing the social acceptability, effectiveness, fairness, and legitimacy of policies and their outcomes. This final point holds particular significance when it comes to emerging and developing agendas, such as inclusive development or climate change adaptation. In these cases, the work is not solely technical in nature, but is closely intertwined with concerns about public acceptance and adoption of new measures (UNESCO Inclusive Policy Lab).

One example of this is the opposition to the Omnibus Law on Job Creation due to its lack of inclusivity in the process. The preparation and discussion process lacks transparency, meaningful participation, and accessibility for people with

disabilities. The government and the House of Representatives (DPR) have never involved or considered groups or organizations representing persons with disabilities from the very beginning of the discussions on the Omnibus Law on Job Creation. Ensuring convenience for people with disabilities goes beyond simply providing information or documents; it also involves making information and documents accessible to them. According to Article 124, paragraph (1) of Law Number 8 of 2016 concerning Persons with Disabilities, it is the responsibility of the central government and regional governments to provide information in a format that can be accessed and understood by individuals with different disabilities.

Language serves as a prime example of a fundamental medium through which one can engage in meaningful participation. It not only reflects perceptions but also encapsulates the historical narrative of a culture, shedding light on the prominence and profundity of certain ideas and beliefs. The very boundaries and structure of a language dictate the thoughts and actions of its users. The intricate relationship between language and cultural context is evident in the case of the deaf community's deliberate selection of sign language as a means to express themselves. Notably, Indonesia boasts the distinction of being the second most linguistically diverse country, second only to Papua New Guinea, with a staggering repertoire of over 800 languages. In Indonesia alone, there are 718 regional languages, predominantly concentrated in the eastern regions, such as Papua, Maluku, East Nusa Tenggara, and Sulawesi. It is notable that this tally does not consider various dialects and

subdialects (Ministry of Education and Culture, 2019)⁷.

Similar to the diversity found in languages, the process of translating sign language also demonstrates a comparable level of complexity in its context. Indonesia is home to two sign languages; the Indonesian Sign Language System (Sistem Bahasa Isyarat Indonesia, abbreviated as SIBI) and Indonesian Sign Language (Bahasa Isyarat Indonesia, abbreviated as BISINDO). The utilization of SIBI has been officially recognized since 1994. Unfortunately, the development of SIBI occurred without the active participation of the deaf community, resulting in a division within the Indonesian deaf community between BISINDO and SIBI users. SIBI was not a product of natural language development within the deaf community, but rather emerged as a consequence of the establishment of a systematic approach for converting spoken language into artificial sign language. Significantly, SIBI exhibits the same grammatical structure as spoken Indonesian, complete with prefixes and suffixes.

Meanwhile, BISINDO is a sign language that appears naturally in Indonesian culture and is used in everyday life. BISINDO then has several variations in each region. This sign language has a grammar that is different from the spoken language used by hearing people in general, covering all elements starting from phonology, morphology, syntax, pragmatics and other elements. A Sign Language Interpreter who visits remote areas and interprets using Indonesian Sign Language (BISINDO), usually first adapts to the local communication system and sign language use patterns. Context and

⁷ <https://petabahasa.kemdikbud.go.id/index.php>

diversity are key to inclusive communication processes. CRPD recommends the Indonesian government to closely consult and actively involve the Indonesian Deaf community to strengthen the accessibility of public information through the use of preferred sign languages, including BISINDO.

Communities of individuals with hearing impairments have appealed to the government to allocate greater attention to the utilization of sign language during formal state occasions. The government persists in employing SIBI instead of BISINDO. Persons who are deaf have submitted a formal request for the government's official adoption of BISINDO. The motivation behind this request is rooted in the fact that BISINDO originates from an Indonesian context, whereas SIBI stems from American Sign Language. Language and cultural context are integral components that contribute to our perception and comprehension of reality. The deaf community's plea for the government's endorsement of BISINDO, as expressed, has yet to be realized.

The government's legalization of SIBI exemplifies, in accordance with White's (1996) terminology, nominal participation, which is frequently employed by more influential actors to confer legitimacy upon development plans. Those who possess less power partake in this practice driven by a longing for inclusion. The deaf community's aspiration for official recognition of BISINDO represents an anticipation of representative participation, which encompasses granting community members a voice in the decision-making process and the execution of projects or policies that impact them. For individuals who wield greater influence, representative participation enhances the prospects of

their intervention being sustainable; for individuals with less influence, it may provide an opportunity for leverage.

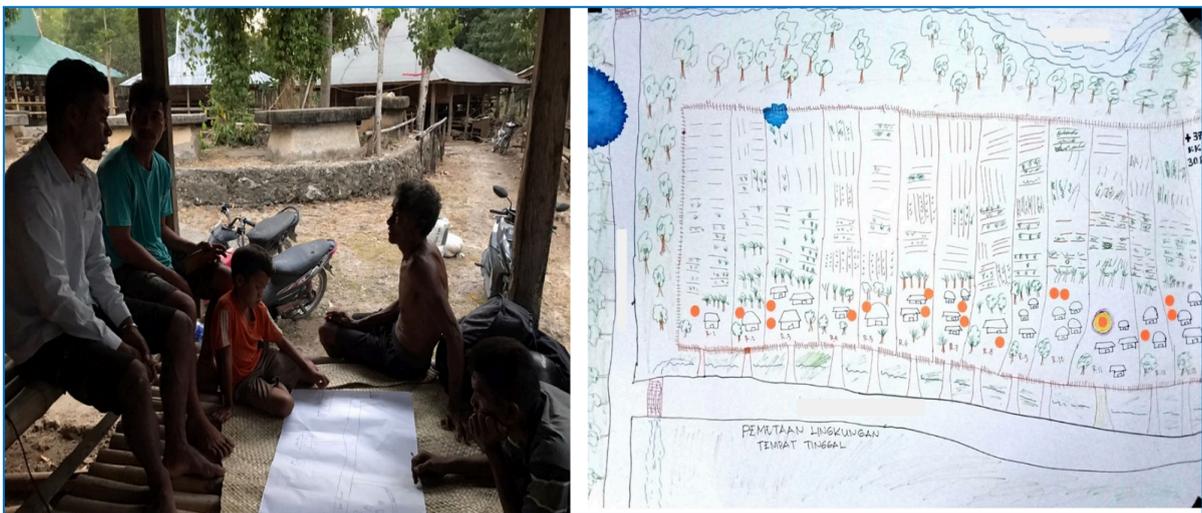
Similar challenges arise in the context of inclusive development within local communities for persons with disabilities. According to ILO (2017), persons with disabilities predominantly reside in rural areas. Village Law No.6/2014 emphasizes the importance of inclusive development, requiring that development planning be conducted through participatory means and involve the entire community, including vulnerable groups such as minority groups, women, persons with disabilities, and the impoverished. Nonetheless, persons with disabilities continue to encounter complex obstacles in their pursuit of meaningful participation in the village development process. Research conducted in several villages in Java and NTT revealed limited mechanisms and opportunities for inclusive participation⁸.

Persons with disabilities, women with disabilities, and impoverished groups are still not adequately represented in village Musrenbang. In contrast, village governments show a lack of awareness about including marginalized groups. In addition, socio-cultural factors have a significant influence on the democratic process within villages. For instance, input from women's groups is not accommodated, and ties of kinship and religion hold more prominence than associations based on residential location. These factors collectively contribute to the lack of power and control that vulnerable groups possess in influencing village development outcomes and policies.

⁸ Ro'fah, et.al. (2022), Prakarsa (2022).

Governments at all levels, including regional governments and even the lowest level of government at the village level, must be empowered to undergo a transformative process that expands their understanding of "disability" and leads to a comprehensive grasp of social inclusion. It is essential for them to possess a fundamental comprehension of what inclusivity and disability truly mean. This crucial step is necessary in order to achieve an inclusive Indonesia by the year 2030. Additionally, this newfound understanding must be accompanied by a

mindset and skill set that enables the implementation of regulations supporting inclusiveness. The village approach is crucial in guaranteeing equal access to essential services for persons with disabilities in disadvantaged areas through enhancing the capabilities of disability alliances. Various key actors, such as village youth, PKH facilitators, and village heads, require capacity building at the village level. These endeavors on a local scale must also be complemented by strengthening the capacity of development planners.



Context mapping is conducted in a collaborative manner by family members and neighbors, with the active involvement of UN community volunteers. This mapping provides a detailed description of the surrounding environment in settlements, including essential facilities like places of worship, infrastructure conditions, access to water, sanitation, and hygiene (WASH), as well as access to healthcare and educational services. In West Sumba, community members engage in mapping their village environment (left image). Similarly, in Jayawijaya, the IDPs themselves participate in the context mapping of one of the IDP camps (right image).

3.2. What's Understood from Contextual Assessment

During this contextual assessment, which was carried out in West Sumba, NTT, and Jayawijaya, Papua, an in-depth and all-encompassing understanding was acquired pertaining to the diverse components of the interrelated system that directly impact the accessibility of

essential services and opportunities for PWDs to lead their lives independently and with a sense of dignity. It was noted that each aspect of this system encompasses a multitude of elements that must be thoroughly acknowledged and taken into consideration in order to bring about an effective transformation within the system and safeguard the rights of PWDs.

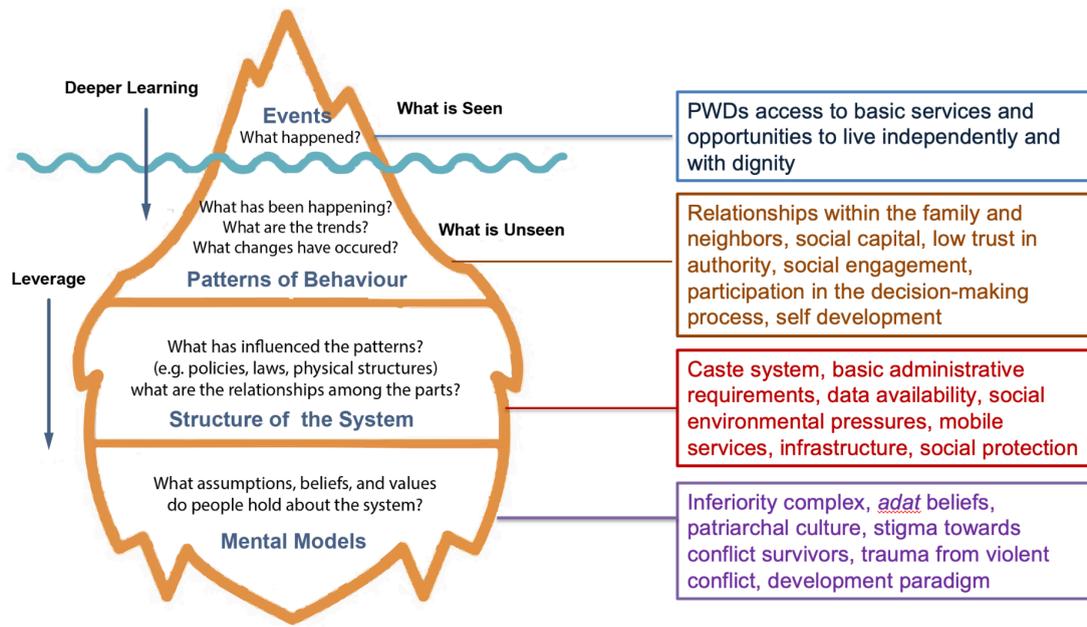
It was observed that each part of this system encompasses a multitude of elements that must be considered in order to effectively transform the system and safeguard the rights of PWDs. Among the various factors that are part of this complex issue, we can identify a sense of inferiority that individuals may experience, the adherence to traditional beliefs and customs, the impact of a culture that values male dominance and control, the presence of social stigmatization towards those who have survived conflicts, the psychological trauma that is a consequence of violent confrontations, and the influence of the prevailing development paradigm. These elements, when taken together, collectively contribute to the shaping of individuals' mental models, which encompass their assumptions, beliefs, and values. The mental models, which are internal representations of how individuals perceive and interpret the world around them, play a crucial role in shaping and influencing the overall functioning and dynamics of the larger system's structure. It is worth highlighting that these mental models possess a reciprocal influence within the broader context of the system's structure, which encompasses a range of factors such as policies, laws, and physical structures. Moreover, it is important to acknowledge that these mental models have a profound and far-reaching impact on various aspects of human behavior, including the intricate dynamics within families and communities. They also significantly affect individuals' participation in the decision-making process and exert an influential force on multiple dimensions of daily life. In summary, the mental models held by individuals have a profound and reciprocal influence within the larger

framework of the system's structure. These mental models not only shape and influence patterns of behavior within families and communities but also have a significant impact on individuals' participation in decision-making processes and various aspects of their daily lives.

The outcomes that emerge as a result of the interactions and interplay between these diverse elements within the system are what ultimately give rise to the fundamental issues surrounding the limited accessibility experienced by PWDs. Furthermore, these outcomes shed light on the insufficient capacity demonstrated by duty bearers and rights holders in fulfilling their respective roles and responsibilities. These fundamental issues encompass a wide range of challenges and barriers that persons with disabilities face in accessing essential services, resources, and opportunities. They also highlight the gaps and shortcomings in the capacity of those responsible for upholding and safeguarding the rights and well-being of persons with disabilities.

The dynamic interactions that occur between the different elements present within the system, such as patterns of behavior, structure, and mental models, ultimately lead to the emergence of the core issues that revolve around the limited accessibility experienced by persons with disabilities (PWDs), as well as the insufficient capacity demonstrated by duty bearers and rights holders. These core issues encompass a wide range of challenges and barriers that persons with disabilities face on a daily basis, thereby emphasizing the urgent need for comprehensive and inclusive approaches that can effectively address and overcome these obstacle.

Contextual systems framework in protecting the rights of PWDs in Jayawijaya & West Sumba



Systemic Issues that Impede Social Inclusion

In the framework of this study, systemic problems are understood as issues that are deeply ingrained in the socio-cultural system or structure, and/or issues that have a wide-ranging impact on the entire system, thus impeding the process of social inclusion. In the context of Jayawijaya and West Sumba, we have identified at least two systemic issues that require attention. The first systemic problem pertains to the cultural circumstances of persistent unequal opportunities, while the second systemic problem relates to the connection between NCDs and social deviation. Recognizing systemic problems is crucial in order to devise the most effective approach to facilitate systemic change.

In the context of this study, systemic issues are understood as problems that have their roots deeply embedded in the socio-cultural system or order. These

problems have a wide-ranging impact on the system as a whole, which consequently obstructs the progress of social inclusion. When we shift our focus to the context of Jayawijaya and West Sumba, we come across at least two systemic issues that demand our attention. The first systemic issue revolves around the cultural backdrop of persistent unequal opportunities. On the other hand, the second systemic issue revolves around the interconnection between non-communicable diseases (NCDs) and social deviation. It is of utmost importance to acknowledge these systemic issues as doing so plays a significant role in devising the most effective strategy to facilitate systemic change.

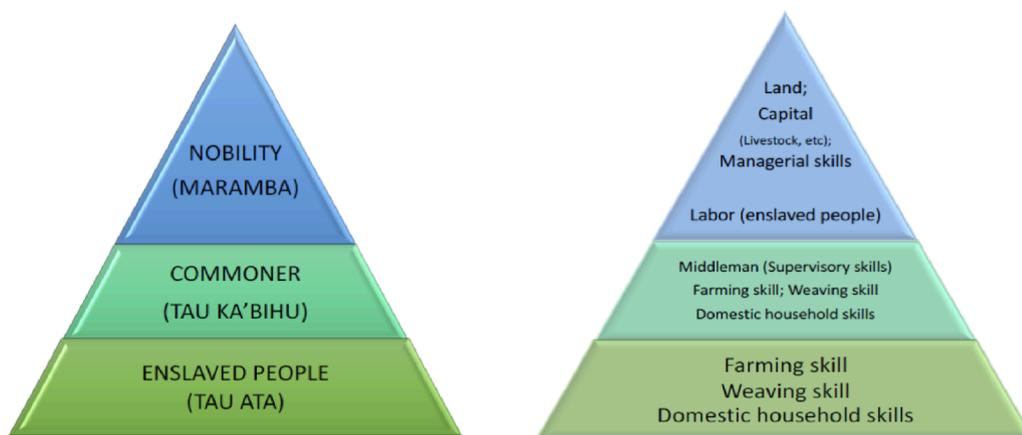
Cultural Context of Persistent Unequal Opportunities

Papua, being one of the provinces with a considerable income (ranking fifth out of the 31 provinces), exhibits a distinct socioeconomic status. In contrast, NTT

province is situated at the bottom of the GRDP ranking (BPS 2021 and 2022). Nonetheless, both Papua and East Nusa Tenggara Province demonstrate a notable level of disparity. These provinces share a common characteristic in terms of a high proportion of residents whose income falls below 50 percent of the median income. The economist from Sumba, who conducted an extensive study on the Inequality of Opportunity and Development Results in Indonesia (ANU 2019) as part of his doctoral dissertation, contemplates the availability of resources and the attention received from the

central government. During our in-depth interview, he expresses his expectation that the central government's priorities and policy formulation process should not solely rely on cost-benefit analysis and economic measurement indicators as benchmarks, but also adopt a rights-based approach that recognizes the equal worth of every individual. Moreover, the existing disparity in the economic sector is further exacerbated by social inequality in the form of caste and indigenous slavery, thereby perpetuating unequal opportunities for development (Raya & Resudarmo 2023).

Caste structure and ownership of factors of production in Sumba



(Raya & Resudarmo 2023)

However, it is important to recognize that the caste system in Sumba operates as a network of oppression, particularly in the intimate yet inferior relationship between slaves and nobles. This relationship is sustained through a combination of incentives and punishments, designed to dissuade the enslaved individuals from seeking independence. The caste system on Sumba operated as a complex web of oppression, with a particular focus on the close yet unequal interactions between

slaves and nobles. To ensure the continuation of these relationships, a combination of rewards and penalties were employed, aimed at dissuading enslaved individuals from pursuing liberation. Loyalty between the enslaved and their masters transcends even the boundaries of life and death, as evidenced by the practice of burying slaves at their master's feet upon the latter's demise, a custom that persisted until the 1990s. Although this practice is no longer

endorsed, the military promptly intervenes to ensure security in the event of a noble's death.

The control of regional leadership in Sumba, which includes both governmental and religious institutions, is primarily under the dominance of the noble caste. This control has resulted in a severe lack of freedom and has limited the ability for political power to shift and change. Furthermore, the two lower castes within Sumba's social hierarchy face an insufficiency in social mobility, which further worsens the existing socio-economic disparities and hampers the development outcomes of the region. In order to effectively address these disparities and promote a more inclusive society, it is absolutely crucial to prioritize and actively work towards redistributing power among the different castes within Sumba's social structure.

Therefore, it is essential to recognize that the issue of social inclusion is closely connected to the deeply rooted caste system that has been historically dominant in this specific cultural setting of Sumba. In this regard, it becomes evident

that the concept of social inclusion cannot be effectively addressed or analyzed without taking into account the pervasive influence and impact of the caste system that has historically shaped and structured the social fabric of Sumba. Any attempt to comprehend the dynamics of social inclusion in this context necessitates an in-depth examination of the complex interplay between the established caste system and the multifaceted processes of social inclusion, as they are inextricably linked and mutually shaping one another.

Fostering class consciousness through a rights-based approach and critically deconstructing the underlying foundations of social structures necessitate collaborative endeavors. This means that in order to promote awareness and understanding of social classes and their impact on society, it is essential to adopt an approach that is centered around the recognition and protection of individual rights. Additionally, it is crucial to critically analyze and break down the fundamental principles and systems that form the basis of these social structures. This requires a collective effort, as it cannot be achieved through individual actions alone.



Reflection on Complexity

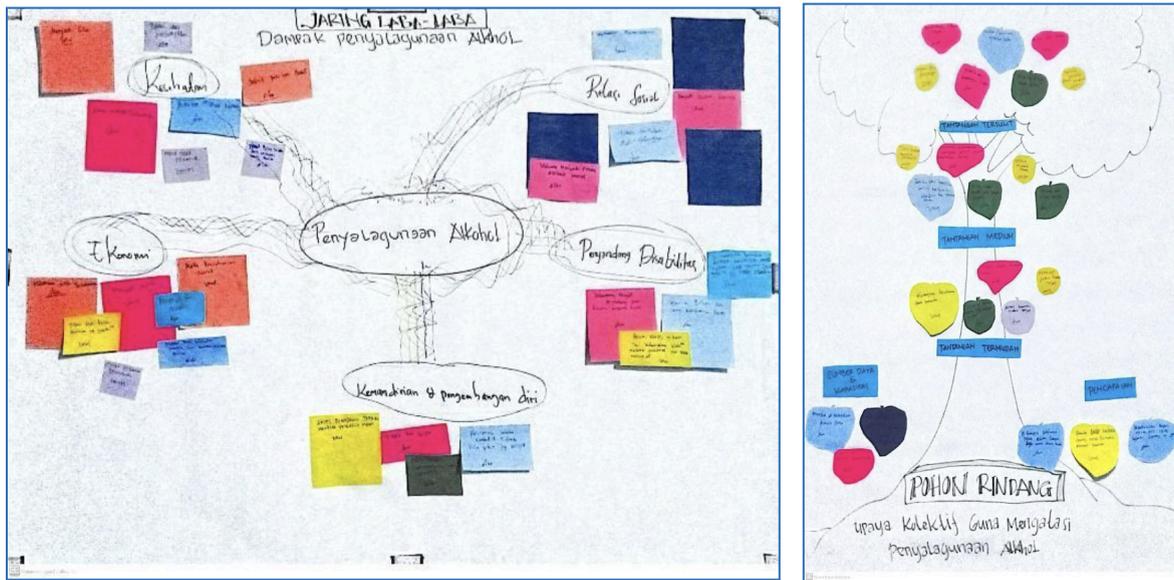
“I have a tendency to express my thoughts openly, without hesitation, when it comes to discussing sensitive topics like indigenous slavery in Sumba. This stems from my sincere belief that my social position allows me the privilege to do so. Despite being born into a noble family and belonging to the highest caste, I actively advocate for the eradication of indigenous slavery on Sumba Island. My inspiration comes not only from my uncle, who serves as a critical Pastor, but also from the education I received at ISS Netherlands. Although my studies primarily focused on Economics, I was assigned various tasks related to poverty mapping. These assignments required me to thoroughly analyze the data, recognize the interconnectedness, and comprehend the underlying causes. As a result, through a comprehensive examination of the root causes within a complex framework, I have strengthened my critical thinking skills. Having personally experienced the benefits of the reflection process, I now employ this approach to raise awareness about social inclusion. Furthermore, my efforts are bolstered by a poverty alleviation program that concentrates on agricultural cultivation field schools.”

UR, inclusion expert and activist- NTT, in-depth interview (2023)

One example of an initiative that aims to initiate this challenging discourse is the comprehensive understanding of the root causes of poverty, which is complemented by introspection, profound empathy, and recognition of interconnectivity. Instead of providing a linear explanation of the underlying reasons (by means of causality logic), the concept of Complexity encompasses the notion of systems thinking, which highlights the significance of perceiving the interconnectedness of diverse components that impact the overall resilience of the system. By thoroughly examining the underlying factors that contribute to poverty, such as economic inequality, systemic barriers, and social injustices, we can gain a comprehensive understanding of this complex issue.

Furthermore, this understanding should be accompanied by introspection, as individuals must critically reflect on their own privileges and biases in order to effectively address the issue of poverty. In addition, a deep sense of empathy is necessary to truly comprehend the experiences and struggles of those living in poverty. This empathy should not only be superficial, but rather profound, as it requires a genuine and heartfelt connection with others. Finally, it is important to recognize the interconnectivity between various social issues and problems. Poverty is not an isolated problem, but rather intertwined with other social issues such as education, healthcare, and gender inequality. By acknowledging and addressing these connections, we can develop a more holistic understanding of poverty and work towards comprehensive solutions.

The Nexus Between NCDs and Social Deviation



A participatory session was held with young individuals aged 18-25 years old to discuss the consequences of alcohol abuse in Jayawijaya. The focus of the discussion encompassed its effects on health, economy, social interactions, persons with disabilities, independence, and personal growth (top left image). Additionally, the session explored the collective endeavors aimed at combating alcohol abuse, including the obstacles faced, available resources and capacity, and accomplishments achieved (right image).

Alcohol abuse is a systemic issue in Papua (IOM 2019). After conducting participatory sessions with young individuals aged 18-25 from diverse backgrounds in Jayawijaya, it is evident that they have significant concerns regarding the mental effects and thought patterns associated with alcohol misuse. These concerns include feelings of unhappiness, anxiety, a diminished motivation to work due to the desire for immediate results, sexist and negative thoughts, and an inability to think positively. This mindset can trigger various consequences, ranging from decreased productivity and loss of livelihood to disability, crime, and violence. As a result of the unfavorable security situation, activities in Wamena, the capital city of Jayawijaya, come to a halt every day at 18:00.

In addition to the direct impact on physical health, many young individuals

describe the effects of alcohol misuse on their overall quality of life as extensive. This is because alcohol is believed to influence daily habits and decision-making processes. Changes in priorities resulting from addiction can lead to a disorganized lifestyle, an inability to maintain cleanliness, and a lack of access to nutritious food and drink. In this situation, alcohol misuse has an impact on the ability to fulfill basic needs, such as the right to health, education, work, and a decent standard of living. The effects on social relationships due to alcohol misuse are also a concern, including dysfunctional family dynamics, conflicts with neighbors, and abuse of power that affects vulnerable groups. This latter issue is caused by the emergence of village leaders who have alcohol-related problems and disregard the rights of the community, particularly vulnerable groups such as persons with disabilities.



A group of young individuals gathered for a discussion on alcohol abuse in Jayawijaya. The session aimed to promote dialogue and gain insights. The participants expressed their concerns and experiences in a secure and inclusive environment. The discussion examined different aspects of alcohol abuse. The session was a pivotal moment for the participants to address the issue collectively and promote positive change.

The most arduous obstacles encountered in addressing the issue of alcohol abuse in Jayawijaya pertain to the transformation of mindsets, the absence of familial discipline, the imposition of penalties by the government, church, and customary law, as well as the dearth of local government regulations concerning alcohol abuse. Several initiatives have been implemented to preempt and suppress the distribution of alcohol. A limited number of villages have taken the initiative to prohibit the dissemination and utilization of alcoholic beverages, such as Sabulama, Wesaput, and Muliama. Additionally, they have established a football field to foster positive engagements among the youth. Nevertheless, given the profundity of the predicaments associated with alcohol abuse, it remains imperative to forge collective endeavors involving the government and non-governmental organizations, bolster law enforcement,

exhibit strong leadership, and engender awareness and knowledge regarding the perils of alcohol abuse.

From a public health perspective, there is still a need for the provision of structural support in dealing with alcohol abuse. Jayawijaya has yet to establish an Integrated Development Post for Non-Communicable Diseases (POSBINDU PTM), which serves as a promotive and preventive measure to identify and manage early risk factors for Non-Communicable Diseases (NCDs) in a comprehensive manner. POSBINDU PTM also attends to disorders resulting from accidents and domestic violence. Managed by the community, POSBINDU PTM constitutes a manifestation of community engagement in the implementation of early detection and monitoring of major risk factors for NCDs, in a regular and systematic manner. Risk factors for NCDs encompass smoking,

alcohol consumption, unhealthy dietary patterns, physical inactivity, obesity, stress, hypertension, hyperglycemia, hypercholesterolemia, as well as prompt follow-up on risk factors identified through health counseling and immediate referral to a primary health care facility.

Social Construction of Disability

Our immersive research provides a comprehensive and in-depth understanding of the intricate and multifaceted process of the social construction of disability. This research delves into the various factors that contribute to the formation and perception of disability status, highlighting the significant influence that perspectives and knowledge play in shaping this construct. It elucidates how societal values and norms, meticulously constructed by the collective consciousness, play a pivotal role in molding and defining disability status.

Moreover, through the meticulous analysis of case studies conducted in two distinct households in West Sumba, we are able to observe and comprehend the intricate relationship patterns that are formed between individuals with disabilities and their families, as well as the broader surrounding environments. These relationships, which are shaped by a myriad of external influences, contribute significantly to the overall social construction of disability. By delving into the nuances of these relationships, we gain a profound understanding of how they intersect with gender dynamics, social status, and social cohesion. It becomes evident that these interrelated factors have a significant impact on the opportunities afforded to persons with

disabilities to experience personal growth and development.

Ultimately, this comprehensive case study serves as a testament to the complex interplay between various elements, such as gender, social status, and social cohesion, in shaping the social construction of disability. It sheds light on the crucial importance of creating a supportive environment that enables persons with disabilities to flourish and attain a high quality of life that is both dignified and fulfilling.

Disability as a Manifestation of Imbalanced Relations

From the immersion conducted, it was observed that the disability status held by the study participants in West Sumba and Jayawijaya was not a mere coincidence but rather a consequence of the socio-cultural construction that exists within these communities. It is important to highlight that this construction is not solely based on one factor, but rather it is the culmination of various imbalanced relations that have a profound impact on the individuals affected. Emic perspectives, which are perspectives that come from within the affected community itself, such as PWDs, their families, and the surrounding environment, shed light on the fact that disability is not an isolated phenomenon but rather a result of the imbalanced cosmological relationship between the individuals concerned, the nature surrounding them, and their ancestors.

Furthermore, it is vital to acknowledge that these imbalanced relationships are not limited to the individual level but extend to the broader social context. In this social context, one can identify

horizontal imbalanced relations that exist between different community groups, specifically in the form of weak social cohesion. This lack of cohesion further contributes to the marginalization of persons with disabilities, as it restricts their access to support networks and resources that are essential for their well-being and inclusion within society. Additionally, there are vertical imbalanced relations that exacerbate the situation, specifically the absence of structural protection mechanisms. This absence manifests itself in various ways, such as the lack of village governance and limited access to public health services, which further compound the challenges faced by persons with disabilities.

Furthermore, it is important to explore the imbalanced relations that exist within the household context, as they play a significant role in shaping the social construction of various identities, including gender, caste, and disability. Warm data obtained from the research

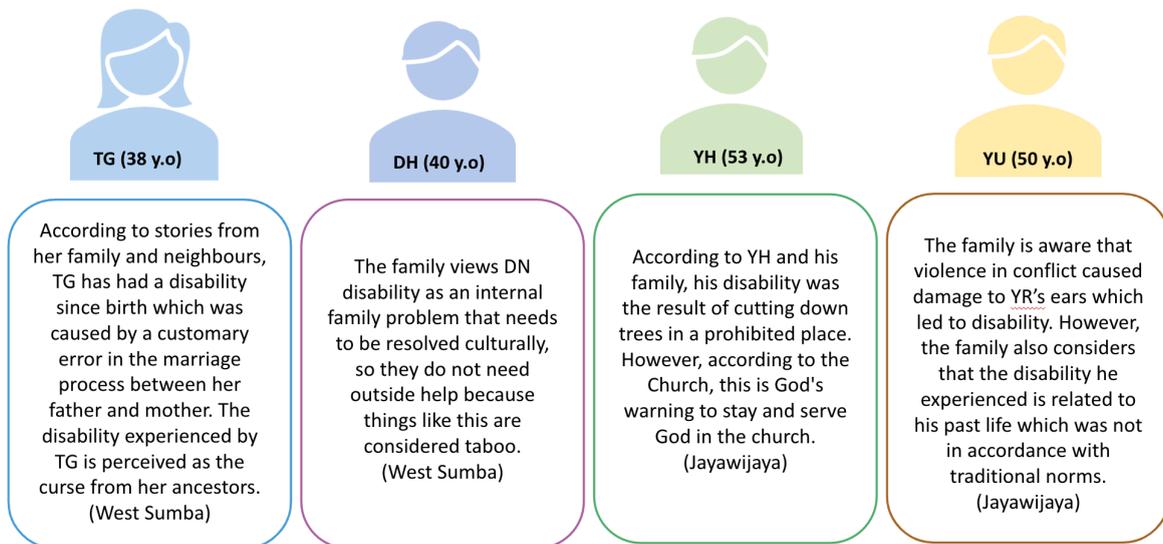
indicates that there are imbalanced relations between family members, which contribute to the perpetuation of stereotypes and discrimination against persons with disabilities. These imbalanced relations within the household not only hinder the overall well-being of persons with disabilities but also limit their opportunities for growth and development.

As a result of these imbalanced relations, persons with disabilities, particularly indigenous women, face exclusion within the scope of households. This exclusion not only restricts their accessibility to essential resources and services but also denies them the opportunity to exercise their basic rights. It is of utmost importance to tackle and dismantle these unequal relationships in order to establish a more inclusive and fair society that respects the rights and dignity of every individual.



Emic Perspectives

What causes disability?



Meet our 4 (four) main study participants as hosts of the immersion carried out by UN community volunteers. Allow us to introduce you to the four extraordinary individuals who have graciously consented to serve as the hosts of this immersive experience, which has been meticulously organized by the dedicated UN community volunteers. By providing us with an intimate glimpse into their lives, these four exceptional study participants will play an integral role in helping us gain a deeper understanding of the diverse and vibrant communities they represent. With utmost gratitude, we welcome them into our journey of exploration and learning, as they generously share their stories, perspectives, and experiences with us. TG and DH have experienced deafness since birth, which means they have been living with this condition from the very beginning of their lives. On the other hand, YH and YU became disabled later in life, when they were already in middle age. YH's disability was caused by a fall

from a high tree, which likely resulted in significant physical trauma. Additionally, YH also had a stroke, which further added to their disability. YU, on the other hand, became deaf due to a firearm explosion, an unfortunate event that caused irreversible damage to their hearing ability.

The diagram above illustrates how cultural construction plays a significant role in shaping the perspective regarding the root causes of disability. The way people perceive and understand disabilities is heavily influenced by their cultural beliefs and values. According to this diagram, physical and mental conditions, including disabilities, are viewed as outcomes of unequal relationships with ancestors and nature. These relationships are established by the individual who is affected by the disability, as well as their immediate family members. This holistic perspective takes into account various factors that contribute to the

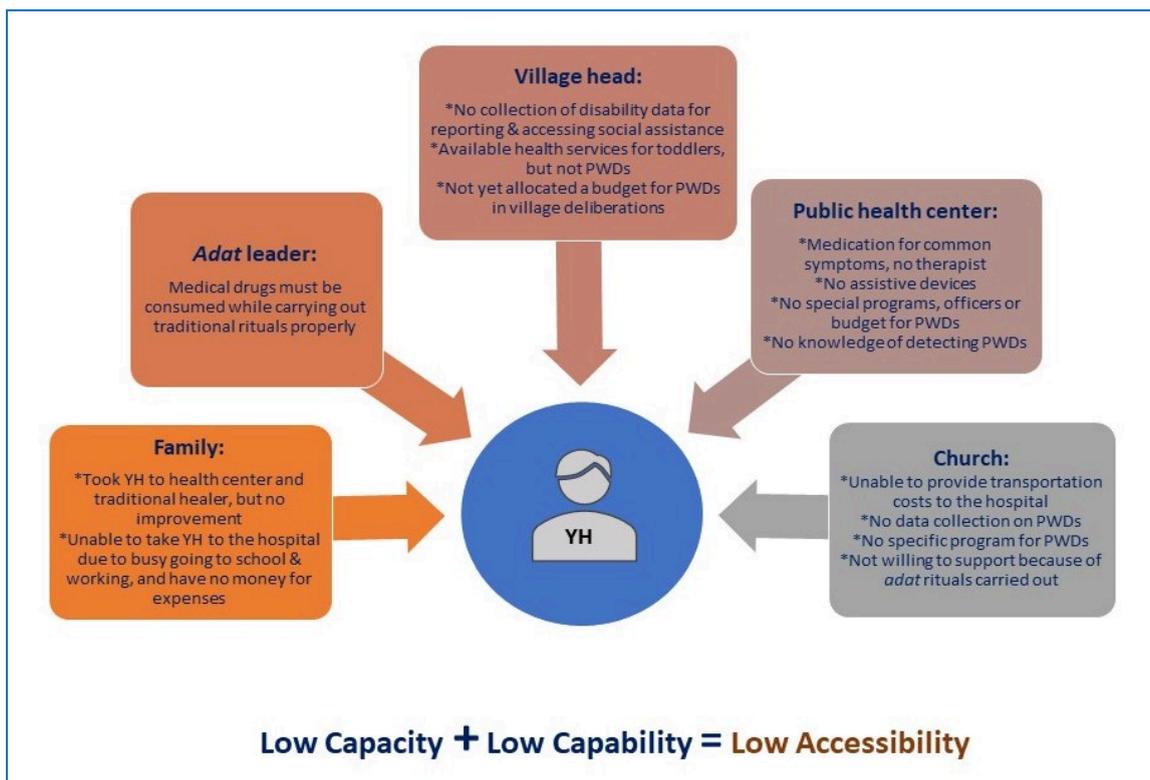
development of disabilities and emphasizes the importance of understanding the recovery process in order to enhance overall well-being.

Indigenous practices and rituals play a central role in this perspective, as they are considered essential prerequisites for healing and self-reflection. These practices and rituals serve as mediums through which individuals can improve their relationships with their ancestors, ultimately leading to a better understanding of their own disabilities and the path towards healing. By considering disabilities as a result of imbalanced relationships, this perspective also gives rise to a sense of shame surrounding disabilities. As a result, disabilities are often regarded as private matters to be dealt with within the confines of the family, rather than being openly discussed in the public sphere.

All treatments are viewed as incapable of bringing about healing unless they are preceded by the performance of indigenous rituals, which hold great significance in their culture. In the past, pastors and congregants would often visit YH and fervently pray for his health, demonstrating their unwavering support and devotion. However, at a later point in time, unbeknownst to the Church, YH's family conducted an indigenous ritual as a means of seeking forgiveness from their ancestors. This ritual was carried out due to the belief that YH had committed an error or transgression, resulting in his

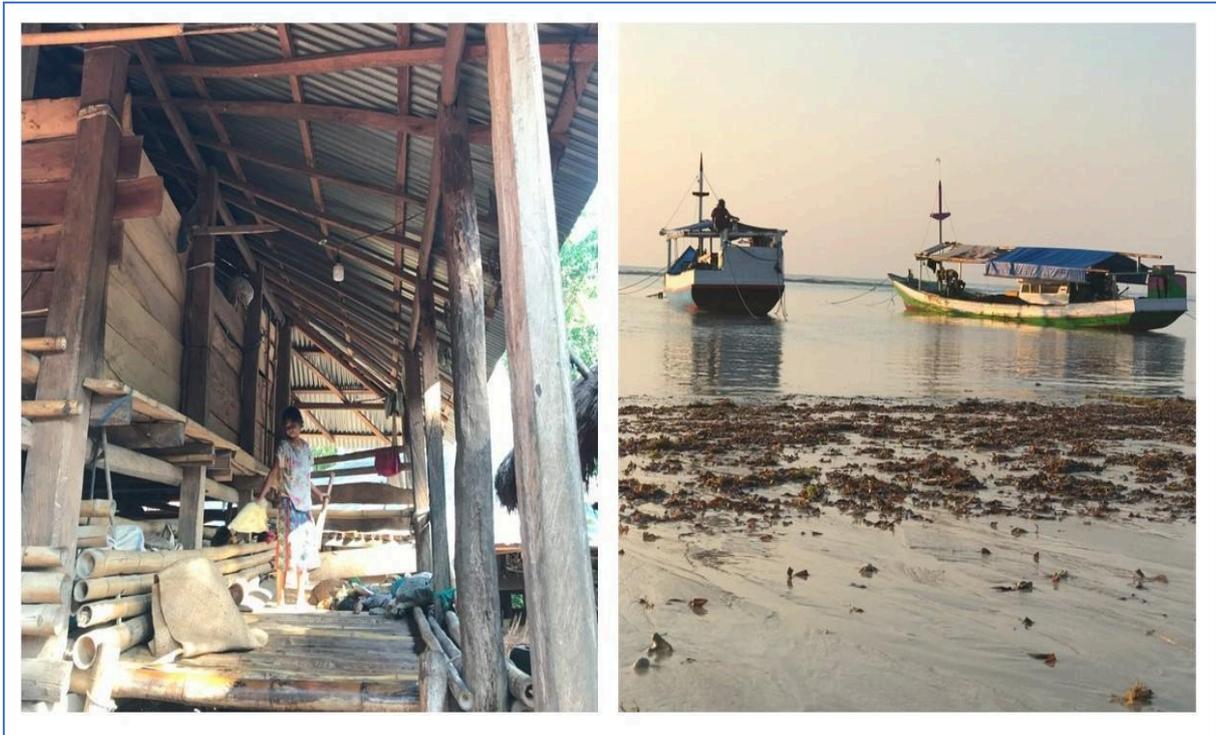
current state of disability. It is important to note that this ritual did not involve any specific healing practices, but rather served as an initial step before seeking medical assistance from the hospital.

Despite having had a large and close-knit family, a wide social circle encompassing both the church and the indigenous community, YH found solace and true understanding solely within the comforting embrace of his wife and children. Recently, however, he has been overwhelmed by the realization that there is no one other than his wife and children who can offer him the much-needed emotional support to navigate through the immense difficulties he is currently facing. The impact of his disability has strained his social ties, not only within his immediate family (as his wife had to make significant adjustments to her employment to cater to his needs), but also within the extended family network. The presence of societal stigma surrounding disabilities has led to a decrease in family visits to their home, further exacerbating their isolation. Moreover, upon discovering that YH's family had resorted to indigenous rituals in an attempt to alleviate his disability, the church distanced itself from them, severing yet another vital source of support. The profound sense of isolation that YH now grapples with has had a detrimental effect on his mental well-being, magnifying the emotional toll he experiences on a daily basis.



The absence of social support for YH is accompanied by the absence of structural support from the village government and the nearest community health center (Puskesmas) to access the necessary health services. The lack of social assistance is primarily due to the fact that there is no data collection on persons with disabilities, which prevents village heads from accessing the necessary support. Furthermore, the lack of understanding about disabilities within the village community leads to a lack of budget allocation for persons with disabilities during village meetings. As a result, the current programs available in the village only focus on providing health services for children under the age of five, completely neglecting the needs of people with

disabilities. In contrast, the Puskesmas acknowledges that there is a shortage of health workers and there is no special budget or program specifically designed for people with disabilities. This includes the lack of visits for patients who are unable to seek treatment at the Puskesmas. Additionally, the Puskesmas only provides general medicines and does not offer therapy or assistive devices for people with disabilities. These essential facilities can only be accessed in the cities, which poses a significant challenge for YH due to their dire economic conditions. It can be inferred that the limited capacity and capability of YH's enabling environment greatly impede their access to obtain the necessary health services.



This is how TG and DH, two individuals who are deaf, start their morning in West Sumba. TG is diligently sweeping the area in front of their house (left image). Meanwhile, DH is meticulously cleaning their boat, getting everything ready for their fishing trip out at sea (right image).

The Interrelationship of Gender, Social Status, Social Cohesion and Opportunities

The recognition and acknowledgment of cultural constructs, such as the belief system prevalent within a given society, serves as a catalyst for further comprehension and insight into the intricate behavioral patterns that ensue as a consequence. This amalgamation of indigenous beliefs, coupled with the presence of caste disparities and other social constructs, such as gender, ultimately fosters a comprehensive understanding of the concept known as horizontal inequality. By delving into this intersectional variable, we are equipped with the necessary tools to grasp the nature and magnitude of each layer involved, which in turn impedes the realization and fulfillment of the

fundamental rights pertaining to the particular group in question.

Within the realms of West Sumba, two individuals by the names of TG and DH, both of whom are deaf, reside in separate villages. These individuals are deeply rooted within their respective indigenous communities, each belonging to contrasting castes. TG, a woman of lower middle economic standing, hails from the commoner or Ka'biyu caste, whereas DH is a man belonging to the noble caste, otherwise known as Maramba. Coincidentally, both TG and DH share numerous similarities; they are the eldest offspring within their families, they lack formal education and literacy, and most notably, they possess no knowledge or understanding of sign language.

The subsequent excerpt extracted from the narrative of TG and DH serves as a poignant illustration of the disparities that exist within the process of attaining and securing their basic rights. The intricate web of familial dynamics and relationship patterns, which either foster an open or closed environment, ultimately determine the extent to which TG and DH are able to cultivate and nurture their self-capacity, involvement, and self-actualization. It is within these unique opportunities that they are able to manifest and embody the individuals they aspire to become. Conversely, the opportunities that they are deprived of, or fail to obtain, inevitably result in a state of disability, wherein the realization of their potential is impeded.

Being Disabled

The lack of knowledge and apathy displayed by parents in relation to TG's condition, combined with the absence of effective communication and support services from external sources, specifically social services in this case, results in a situation where families residing in their own homes remain unaware of the concept of disability and the entitlements associated with it. In the specific case at hand, the family had come to accept TG's condition, who had been deaf since birth, without making any effort to seek medical assistance or explore alternative indigenous methods to enhance TG's well-being. On a daily basis, TG would engage in household chores such as sweeping the backyard, thereby contributing to the preparations for cooking within the household. However, once the cooking was completed, TG would find themselves in a state of isolation, devoid of meaningful communication and lacking any other form of activity. The sole means of communication available to TG would be

through the implementation of a specific code, wherein a small stone, resembling a kernel of corn in size, would be thrown at the part of the body capable of eliciting a response, thereby enabling TG to react or identify the source of the stone.

As a consequence of the circumstances, TG can only be observed engaging in the act of closely monitoring the actions of individuals within the confines of their own homes or amongst their neighbors. It proves to be quite challenging for TG's family members or acquaintances to fathom or comprehend the true intentions or desires that TG harbors with respect to their day-to-day necessities. Typically, it is solely when TG becomes vocally expressive and emits piercing cries that the family or neighbors are able to decipher the fact that TG yearns for a refreshing cup of coffee. Such occurrences serve as the sole opportunity for TG to effectively articulate her innermost thoughts and desires. Regrettably, TG's family has never extended an invitation for her to venture beyond the boundaries of her residence, thereby rendering TG in a state of isolation from any form of social interaction and making it exceedingly arduous for her to cultivate and nurture interpersonal relationships. This unfortunate predicament materializes due to the erroneous assumption held by those in her immediate vicinity that TG is bereft of the capability to carry out even the most menial tasks as a result of her deafness.

It is precisely this line of thinking that hinders TG from actively participating in any familial discussions pertaining to matters of import. In fact, she is never accorded the opportunity to express her personal viewpoints on any subject matter, even when it directly concerns her own well-being. Instead, such

decision-making processes are predominantly orchestrated by her extended family, thereby effectively excluding TG from the decision-making process. With regard to her attire and sustenance, TG's mother and sister-in-law undertake the responsibility of tending to her clothing and nourishment needs. TG herself is never directly involved in the provision of her own sustenance and garb,

nor is she ever invited to accompany her family members to the marketplace for the mere purpose of leisurely perusing the merchandise or procuring her own necessities. Over the course of an astonishing 38 years of her existence, TG has resided solely within the vicinity of her immediate residential neighborhood, never venturing beyond the confines of her own dwelling.



TG was seated in solitude during the afternoon in close proximity to her abode. Despite being in bustling surroundings, TG frequently finds herself in isolation amidst the multitude due to the absence of interpersonal connections. Social exclusion is the cause of her solitude, and she endures the absence of companionship.

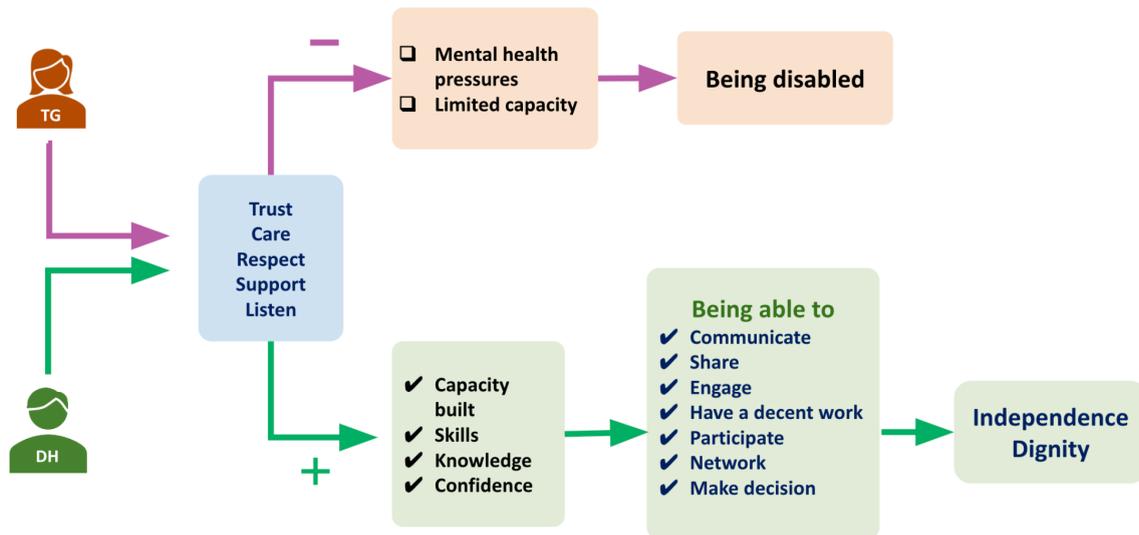


DH's house where he lives with his siblings and family. The many buffalo head horns displayed in front of the house resulted from indigenous rituals carried out by parents and previous generations who were part of the noble caste. When the picture was captured, DH himself was out at sea. The family eagerly awaits his return for the decision-making procedure. They hold DH's status as the eldest son in high regard, and thus take his opinion into account in diverse affairs.

DH is widely known and highly regarded within the local village community as well as among the coastal inhabitants due to his occupation as a skilled fisherman. Renowned for his cleverness and expertise in catching fish and skillfully mending broken nets, DH has earned a reputation among his circle of friends for his exceptional abilities in these areas. It is precisely this proficiency that endears him to his employers, who greatly appreciate his valuable contributions. Through his occupation as a fisherman, DH is able to not only fulfill his own personal needs but also provide financial support to his younger siblings who are currently pursuing their education. Remarkably, DH remains blissfully unaware of his own disability, as his focus and dedication lie solely in his craft. However, given his

extensive experience and vast knowledge in the field of fishing, it is only fitting that DH be acknowledged and celebrated by the general public. His expertise encompasses a wide range of essential aspects, including a profound understanding of fishing vessels, the ability to discern the optimal time for venturing out to sea, and an in-depth comprehension of various fishing equipment such as rods, nets, and trawls. Furthermore, DH possesses a remarkable skillset in effectively handling damaged shrimp trawl nets and seamlessly mending any flaws in their intricate weavings. It is through this wealth of knowledge and expertise that DH is able to maintain his independence and successfully cater to his daily requirements.

Social Construction of Gender, Caste and Disability



Apart from the opportunities that arise from the various relationship patterns within the family, which ultimately give rise to differences in TG and DH's ability to fulfill their potential, there is a shared aspect between TG and DH. It is worth noting that none of them received the necessary support in the form of social protection from the government.

In the case of TG, data exclusion has been a significant concern. Due to her lack of an ID card, she remains invisible and undetectable within the government system. Consequently, she is unable to exercise her rights as a citizen and lacks the necessary protection afforded to persons with disabilities. Regrettably, TG has never received any form of social assistance solely because she does not possess an ID card. In an attempt to rectify this situation, the village head has visited her household to assist with obtaining a family card. Additionally, the village head

has suggested that TG visit the local sub-district office to have her photograph taken, thus facilitating the process of acquiring an ID card. However, TG has not yet obtained an ID card as she has not undergone the aforementioned photo shoot. It is disheartening to note that the family did not adequately address the Village Head's recommendation for TG to refrain from participating in the general election due to her lack of an ID card. Despite the fact that all other family members possess valid ID cards, they have shown a lack of concern regarding TG's situation, seemingly relegating her to a perpetual existence within the confines of her neighborhood.

In direct opposition to TG, DH is able to be detected within the system due to the fact that he possesses an identification card. Additionally, DH has been officially registered as a recipient of the PKH program. Unfortunately, it turned out that

DH did not actually receive the PKH assistance that he was entitled to. In a solitary occurrence during the year 2022, DH was provided with the PKH social assistance in the form of cash at the village office. Interestingly, during the PKH process, Deni did not receive his ATM card. After confirmation from his family, it was discovered that the PKH/ATM card had not been obtained from the responsible officer overseeing the PKH program. According to the officers, the card was given to a member of DH's family. On the other hand, DH's family denies ever receiving the card.

Despite reporting the officer's actions to the social services department, the family did not receive a resolution to their situation. The family also sought help from technologically skilled neighbors who used an application to investigate. The investigation revealed that DH's name remained in the system, even though it was clear that he did not receive the assistance he was entitled to. Eventually, the family lost faith and decided to stop pursuing justice.



DH and his sibling are having a conversation at his sibling's residence. This exchange of thoughts and ideas has been going on for quite a while, ranging from family matters to societal concerns. Despite the fact that neither of them knows official sign language, they have devised their own unique sign language to effectively communicate (left image). DH is taking a moment to relax with his relative, who is sharing video footage on the veranda of their house. This is a well-deserved break after his fishing trip. The view from behind captures the heartwarming sight of family members gathering together to create a warm and inviting atmosphere at home. The conversation includes every individual, ensuring that everyone feels involved and included (right image).

Complex Factors Influencing Well-Being

Our immersive research has yielded valuable insights into the intricate and multifaceted factors that significantly impact the overall well-being and quality of life of persons with disabilities. This is unequivocally exemplified by the undeniable presence and influence of a wide range of social and environmental pressures, which directly and indirectly affect the accessibility and ability of persons with disabilities to meet their most fundamental and essential needs. Through in-depth examination and analysis of two distinct households located in Jayawijaya, our comprehensive case studies have unequivocally demonstrated that persons with disabilities face numerous multidimensional challenges that not only place them in a position of heightened vulnerability but also expose them to a myriad of risks and potential crises.

It is important to note that this vulnerability stems from the initial condition of deprivation, which serves as a precursor and catalyst for the subsequent exposure to various risks and crises. Furthermore, it is vital to acknowledge that the detrimental consequences of these challenges extend beyond the individuals with disabilities themselves and also significantly impact their family members and loved ones. Consequently, this particular case study has provided us with a profound and nuanced understanding of the intricate and cyclical relationship between disability and deprivation. On a related note, another compelling case study has shed light on the detrimental effects of social and environmental pressures on the resilience of the system as a whole. It is evident that these pressures weaken the system's

ability to cope and adapt, ultimately leading to displacement and the onset or exacerbation of disability. This exemplifies the far-reaching and pernicious effects that social and environmental pressures can have on the lives of persons with disabilities, illustrating the urgent need for comprehensive and holistic interventions to address and rectify these pressing issues.

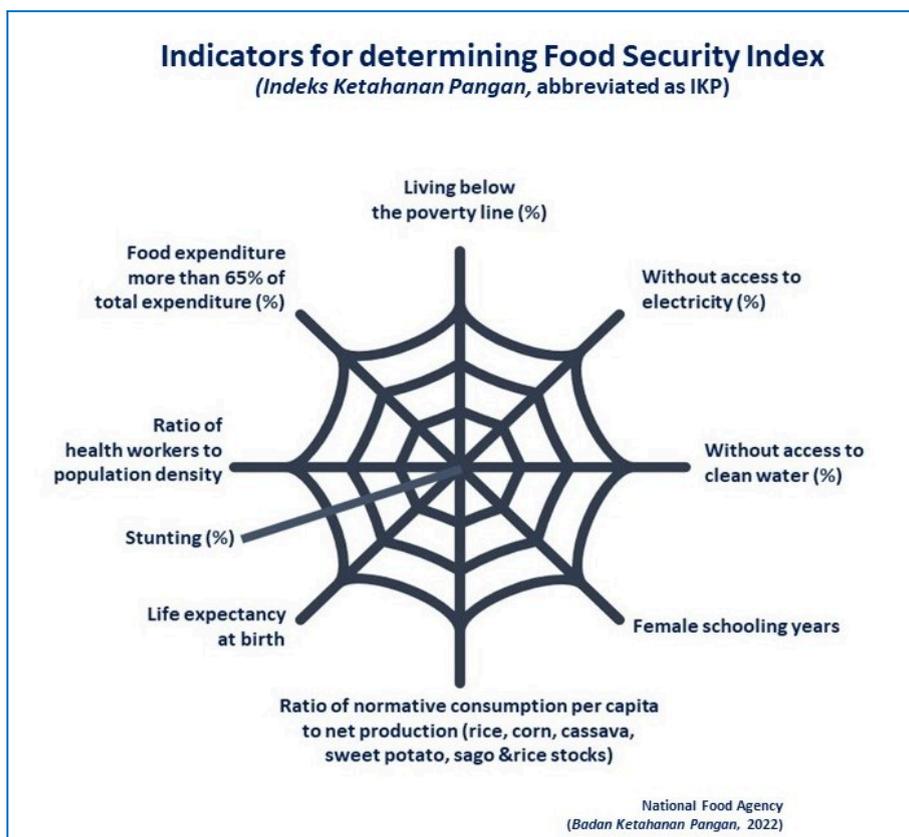
Social Environmental Pressures of Accessibility

The primary factor affecting accessibility in West Sumba and Jayawijaya is the limited availability of essential services like education and healthcare. We have identified various significant elements, both physical and non-physical, that influence the level of accessibility. Firstly, there is a significant geographical remoteness, with considerable distances separating residential areas from health and education centers. It takes several hours of walking or using public transportation, which costs IDR 50,000 per person, to reach the nearest health center. The community often expresses their frustration by saying, "Even though there is a Puskesmas, we still have to bear the expenses for at least two individuals, including the sick or people with disability and their companion. Consequently, we are unable to seek treatment due to a lack of funds for transportation." The absence of resources greatly impacts the situation.

The interconnectedness of the distance element, also known as remoteness, with other elements, specifically the availability of resources to cover transportation costs, is of significant relevance when considering the overall accessibility to health services. This is due to the fact that the distance element is not an isolated

factor, but rather intertwined with various other elements that collectively contribute to the accessibility of health services. By acknowledging this interconnectedness, it becomes evident that the mere presence of health services is not sufficient in itself, as the accessibility to these services is greatly influenced by factors such as the

availability of resources to cover transportation costs. Therefore, it is crucial to recognize the complex relationship between the distance element and the availability of resources, as they both play a crucial role in determining the accessibility to health services.



The indicator of the food security index demonstrates the practical application of the complexity principle, which effectively showcases the numerous interconnected elements that contribute to the overall accessibility and level of food security. It is important to recognize that the level of access to basic services plays a crucial role in determining the Food Security Index (commonly referred to as IKP), a fundamental component of the Food Security and Vulnerability Atlas (FSVA).

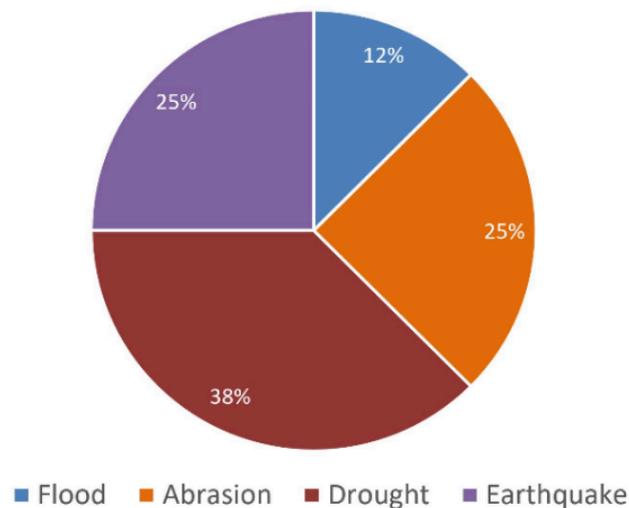
The IKP serves as an indispensable tool in evaluating the progress made in regional food and nutrition security, providing comprehensive rankings of the achievements in regional food security. The set of indicators that make up the IKP encompasses a wide array of intricate and interrelated factors.

It is essential to note that a low IKP not only signifies the presence of poverty but also indicates the limited availability of

vital resources, including nutrition, healthcare services, electricity, and clean water. As emphasized by the National Food Agency (2022), the province of Bali, which is one of the 34 provinces in Indonesia, stands out with the highest IKP score of 85.19. On the contrary, NTT ranks 27th with a score of 68.42, while Papua finds itself at the bottom of the list with a

score of 37.80. Taking a closer look at the specific districts within Papua, namely Nduga, Intan Jaya, Central Mamberamo, Puncak, and Lanny Jaya, it becomes evident that these areas exhibit the lowest IKP scores. West Sumba's IKP comes relatively close to the provincial average, scoring 68.08, whereas Jayawijaya falls below the average with a score of 25.00.

Disaster Frequency in West Sumba



Source: BNPB, 2023

Environmental pressure plays a role in affecting the attainment of indicators in the food security index. According to BPS data from 2021, NTT ranked highest with 454 cases out of 2,570 drought occurrences. Due to the increasingly widespread drought, the NTT Provincial Government has issued a drought emergency alert since the end of April 2023. It is anticipated that the number of residents impacted by this drought will continue to rise. Based on data from BMKG, this drought is closely linked to the El Nino phenomenon, which has led to an unusually prolonged dry season in Indonesia. El Nino is a natural

phenomenon characterized by hotter climate and a longer dry season. The Meteorology, Climatology, and Geophysics Agency (BMKG) has estimated that the peak impact of El Nino will be experienced in August-September 2023 since July of the same year. Additionally, BMKG predicts that the 2023 dry season will be exceptionally dry compared to normal conditions. This drought has a significant impact on IKP in NTT, particularly in terms of access to clean water.

Apart from environmental pressure, the low level of food security in Jayawijaya cannot be divorced from socio-cultural

elements. The indigenous population of Jayawijaya has been consuming sweet potatoes as a staple food for generations. However, starting from 2010, sweet potato plantations in Jayawijaya have witnessed a decline in production. The reason behind the unavailability of sweet potatoes is the lack of public will and awareness regarding the consumption of local food. The provision of rice assistance for the poor (abbreviated as Raskin) has fostered a culture of dependence on rice, which has gradually replaced sweet potatoes. Indigenous men are hesitant to cultivate sweet potato gardens due to the easy availability of rice. This is further compounded by a lack of understanding regarding the utilization of cash assistance to fulfill basic needs, consequently driving consumption patterns. The impact is keenly felt by indigenous women, who face challenges in meeting the needs of their families. Up to this point, the Agriculture Service has not extended any assistance or guidance with regards to the

food situation. Consequently, sweet potatoes have become increasingly scarce, and their prices have surged, making access to sweet potatoes progressively more difficult.

The scarcity of pigs, which serve as an essential component of social reproduction among indigenous communities in both Papua and NTT, is subject to a similar phenomenon. The shortage of pigs in NTT, specifically in West Sumba, has been attributed to the occurrence of African Swine Fever (ASF) since the conclusion of 2019. By 2020, hundreds of thousands of pigs in NTT had succumbed to this disease. In the period between December 2022 and January 2023, the Head of the Animal Health Division of the Livestock Service of East Nusa Tenggara Province (NTT) recorded the sudden death of 233 pigs. Furthermore, it is suspected that this mortality rate may also be attributed to African Swine Fever (ASF).



Pig jaws hang from the ceiling of DH's house, left by his parents and previous generations. Pig jaws are a source of pride as proof of involvement in traditional rituals (left image). DH and his family's pigsty is currently empty. Currently they do not have any pigs due to the ASF virus outbreak (right image).

Pigs in NTT Province are considered to be of significant value, not only in terms of their economic contributions but also their role within the socio-cultural framework. These animals are employed during ritual ceremonies, particularly in the context of weddings and the passing of a family member. Pigs are bestowed as a reciprocal gift from the bride in response to the dowry received from the groom. Additionally, pigs are required for other occasions, such as "first communion" ceremonies. The scarcity of pigs resulting from the ASF virus has had a profound impact on both socio-cultural and economic aspects of life. For instance, during customary weddings, women are compelled to pay twice the usual price. Meanwhile, socio-cultural factors underpin the limited availability of pigs in Jayawijaya, Papua.

Since 2012, indigenous communities in Jayawijaya have ceased to maintain pigs as they once did. In the past, a single-family unit could possess more than 10 pigs, whereas presently, they keep a maximum of 5 pigs, or in some cases, none at all. Despite the provision of assistance from the Animal Husbandry Service in the form of pig seeds and treatment for various livestock, including pigs, the number of pigs continues to dwindle. The waning enthusiasm for preserving ancestral culture, coupled with a reliance on government aid in the form of monetary

assistance, explains the reluctance to engage in pig rearing. The aforementioned depiction elucidates the interconnection between the environmental crisis, food security, and cultural resilience. This is owing to the fact that, within the context of indigenous communities, food and livestock, particularly pigs, hold a greater social and cultural worth in comparison to their mere nutritional and economic value.

Descriptions collected from the field provide evidence that the interconnectedness among different indicators in the food security index (IKP) can significantly impact the ability of PWDs to not just acquire, but also enjoy and benefit from their basic rights, as well as influence their overall well-being. If we learn deeper into this issue, we will discover that there are various consequences. On one hand, there is a ripple effect where access to a specific resource (such as clean water) can have a major influence on accessing proper nutrition. On the other hand, in a structurally unequal context where equal access is lacking, a domino effect will occur. To illustrate these two aspects of the phenomenon, let's consider the following two examples. A thorough examination of the various dimensions and intricacies of these impacts is vital when formulating strategies to bolster the system's resilience.



The well, which was only a little over one month old at the time it was photographed, was excavated and coated by the village community, which is made up of 12 households (left image). Although the well water is not yet suitable for drinking, it is still consumed due to the scarcity of clean water. Even though there are still no toilets with septic tanks available, the presence of wells is extremely beneficial because previously the villagers had to travel a considerable distance of more than 1 kilometer to collect water. The accessibility of water encourages families to cultivate vegetables for their daily consumption (right image). (West Sumba)



YH, an individual who has a physical disability, is situated in front of his residence. He is unable to move without assistance as he is paralyzed and does not possess any assistive devices. The area where YH's family resides encounters difficulties in accessing clean water for drinking and cooking. Moreover, their customary abodes are constructed with thatched roofing material, which hinders them from collecting rainwater. The majority of households in the area lack proper sanitation facilities, leading to the practice of defecating and urinating on the grass.

Vicious Cycle of Disability and Deprivation

People with disabilities have a higher likelihood of falling below the national poverty line compared to their non-disabled peers. Consequently, persons with disabilities are more prone to experiencing poverty and often have to rely on their struggling family members for support (TNP2K, 2019). Bappenas, the Indonesian Ministry of National Development Planning, has described that in the year 2020, the highest poverty rate for people with disabilities was observed in Papua Province, specifically at 20.62%. This was followed by DIY (20.16%) and NTT (20.02%). These statistics indicate that 1 out of every 5 persons with disabilities in these three provinces was categorized as poor. This alarming data sheds light on the strong correlation between disability and poverty.

To illustrate this connection further, let's delve into the story of YH, an individual with physical disabilities residing in Jayawijaya. It is important to note the preconditions that existed before the occurrence of the shocking events in YH's life, namely work accidents and strokes. These preconditions already signify a significant level of deprivation in YH's life. However, the inability to overcome these shocks had a multiplier effect on the extent of YH's deprivation, which also had a profound impact on the well-being of his children and wife. This cascading effect of deprivation extends beyond just the individual experiencing disability, but also affects their immediate family members. Additionally, deprivation is not limited to the economic aspects of life. It also encompasses social and structural domains such as trust, social cohesion,

and social protection. This multidimensional deprivation creates a daunting challenge in breaking the cycle of poverty and disability. The interconnectedness between disability and poverty becomes evident as individuals face obstacles in various aspects of their lives due to their disability, which in turn perpetuates their impoverished state.

YH and his family currently live in conditions that are characterized by limited access to basic necessities. This includes lacking proper education, living in poverty, and facing challenges such as the absence of clean water, electricity, and sanitation facilities. It can be observed that, considering the various indicators available, both YH and his family experience a significant level of food insecurity. Their ability to sustain their livelihood primarily depends on the availability of natural resources and the products derived from gardens.

In the year 2015, an unfortunate incident occurred when YH fell from a considerable height of approximately 5-6 meters while engaged in the task of chopping wood for the purpose of constructing a fence. Regrettably, he did not receive immediate medical attention and continued to endure the effects of his injuries for several months. The accessibility to health facilities was a challenge for YH, as he was unable to afford public transportation, which was the primary means of reaching these facilities. Nonetheless, with the assistance provided by the Church, YH's family managed to transport him to a hospital using the BPJS KIS program, a form of social protection.



The narrative of YH's journey eloquently tells the story of the events that unfortunately resulted in disability, while also offering heartfelt reflections on the incredible resilience shown during that challenging period. The moving story is skillfully retold by YH and his caring family, with invaluable help from a compassionate UN community volunteer who used the powerful 'river of life' media. It is worth mentioning that the visuals accompanying this narrative were thoughtfully designed by YH's own children, adding an extra layer of personal significance.



On a Sunday morning, YH and his children can be found in their indigenous house with a thatched roof and woven walls. Inside this humble house without windows, YH and his children are seen eagerly examining the stationary provided by the UN community volunteer. The cascading impact of disability weighs heavily on YH's mental well-being, as he is saddened by the immense pressure his wife and children endure. However, YH's children serve as a source of inspiration and optimism, guiding him through the challenges that arise in his life.

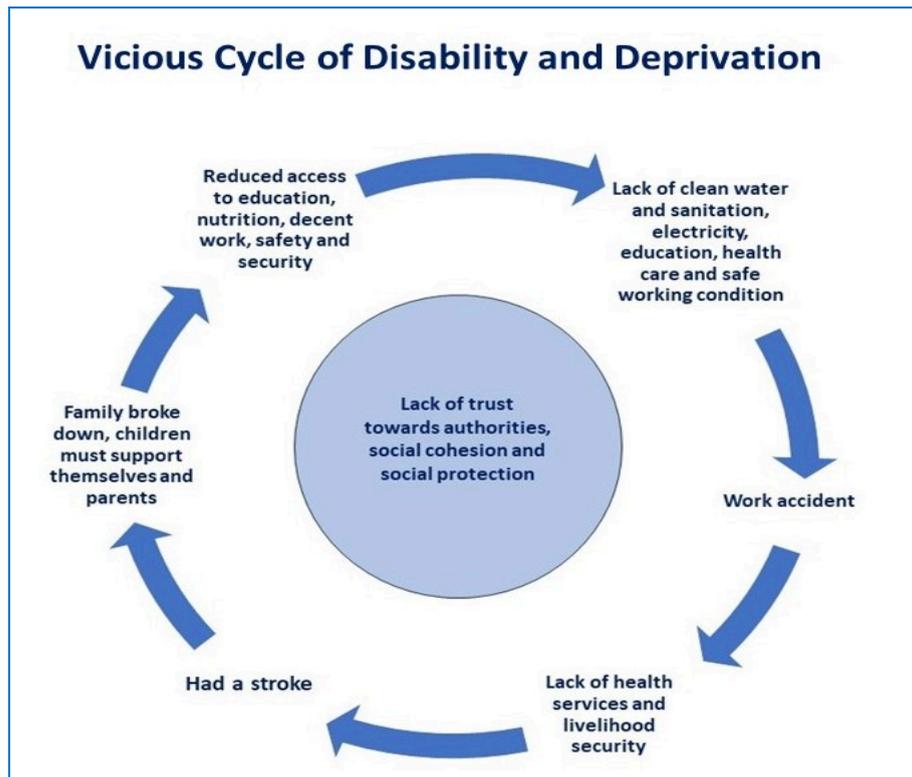
Following the hospital visit, YH faced tremendous economic pressure to provide for his children and wife, which resulted in his decision to persist with work despite his physical limitations. Unfortunately, he disregarded the advice given by his doctor, which recommended that he take a period of rest to aid in his recovery. This disregard stemmed from YH's lack of trust in authorities and subsequently led him to neglect the prescribed medication. This led to a worsening of his condition, exacerbating the challenges he was already dealing with.

In the year 2018, an unfortunate event occurred in his life, as he experienced a stroke which had a severe impact on his physical well-being. This stroke not only caused him immense suffering, but it also led to a further deterioration of his already fragile physical condition. The consequences of this stroke were far-reaching, rendering him disabled and unable to perform the simplest of tasks. As a direct consequence of his disability, the economic situation of his family began to spiral downwards, taking a turn for the worse. Prior to the onset of his disability, he and his family were content with a modest and satisfactory lifestyle, devoid of any significant hardships. However, the stroke changed everything drastically, leaving him incapable of providing any form of support for his household.

Consequently, his wife, in an attempt to alleviate the financial burden and secure a stable source of income, made the difficult decision to relocate to a village approximately 3 kilometers away. In this new village, she embarked on the venture of raising pigs and cultivating a garden.

Despite the distance, she would occasionally make the arduous journey on foot to visit her family, ensuring she carried a generous supply of sweet potatoes to sustain them. Presently, the responsibility of survival and maintaining their father's existence falls onto the shoulders of their children, who find themselves in a relentless struggle to make ends meet.

These five resilient children, each with their own unique set of challenges, embark on a daily journey of perseverance. With a determination that knows no bounds, they embark on a four-kilometer walk to school each morning, fueled solely by their own resilience, as breakfast is a luxury beyond their reach. Upon the conclusion of their academic pursuits, they eagerly lend a helping hand in the garden, diligently searching for nourishment to feed the pigs. In a testament to their resourcefulness, the children then take it upon themselves to sell the sweet potatoes and vegetables they have harvested to the local market. The proceeds from these sales are then utilized to acquire their basic necessities, ensuring their survival in the face of adversity. As evening approaches and darkness descends upon the land, the children are finally reunited with their father, for whom this will be the first meal of the day. In this way, they find solace and comfort in the company of their family, savoring this much-needed sustenance that provides them with the strength to persevere through the trials and tribulations that life has presented them with.



Displacement and Disability

The establishment of Papua Pegunungan (mountainous Papua) Province is the outcome of the expansion of Papua Province, which was officially declared after the People's Representative Council (DPR) successfully passed three bills (RUU) that sought to establish three New Autonomous Region (DOB) provinces in Papua on the momentous day of Thursday, the 30th of June in the year 2022. Papua Pegunungan Province encompasses a number of regencies, namely Jayawijaya, Bintang Mountains, Yahukimo, Tolikara, Central Mamberamo, Yalimo, Lanny Jaya, and Nduga. This province, Papua Pegunungan, finds itself grappling with a myriad of social, political, and environmental challenges simultaneously. The indigenous people residing in the Papuan mountains bear the brunt of the adverse effects brought about by climate change.

The National Disaster Management Agency (BNPB) has recorded that the residents of Lanny Jaya encountered an alarming occurrence of extreme weather, namely frost and hail, during the month of July in the year 2022. This unfortunate event took place within their plantation areas, affecting the lives of more than 2,400 individuals. The consequences of this extreme weather were not limited to the destruction of plantation lands, which resulted in the loss of valuable food sources and livelihoods, but it also tragically claimed the lives of both adults and children.

Similarly, the central mountainous region of Puncak Papua Regency found itself facing a grave hunger crisis that claimed the lives of many individuals due to the relentless drought that plagued the area until the month of August in the year 2023. The extreme weather conditions

experienced in the Papua Mountains have wreaked havoc on the food systems, ultimately leading to famine. Furthermore, the remote geographical location of the Puncak Regency presents a significant obstacle when it comes to providing emergency assistance to the famine-stricken victims. The ability to reach this location is severely hampered, as flights can only be accessed by small planes and are entirely dependent on weather conditions, thereby limiting their availability to specific times.

Socio-political pressure is encountered not only by Papua Pegunungan but also by other mountain communities such as Nduga Regency. This particular region has experienced military operations due to armed clashes between armed groups and the Indonesian army. As a consequence of this conflict, there has been a significant influx of IDPs, which stands for internally displaced persons, consisting of Nduga civilians who have fled to various locations in Papua, including Jayawijaya Regency. According to the records of the Commission for Missing Persons and Victims of Violence (Kontras) as of December 2022, the number of displaced civilians reached a staggering 60,642 individuals, out of which 732 have tragically lost their lives. This devastating armed conflict between the military and separatist groups has caused immense suffering and displacement.

The repercussions of this dire situation extend beyond the displacement of individuals from their homes. The IDPs, particularly the children among them, are also facing the harsh realities of malnutrition. Volunteers working with the IDPs have observed that by October 2023, the number of IDPs in Jayawijaya Regency alone has surpassed 24,000 individuals. It is disheartening to note that 70% of these

IDPs are women and children, and approximately 40 of them are people with disabilities. The IDPs have sought refuge in various locations within Jayawijaya Regency, namely Ilekma, Wilekama, Wouma, Kama, Hom-hom, Hobi-kosi, and Sekom. These sites serve as the temporary homes for the IDPs, providing them with shelter and some semblance of security amidst the chaos.

The challenges faced by the people of Papua Pegunungan are manifold, and the region has rightfully earned the nickname of an extreme area. This sentiment is voiced by a disability activist who actively assists in addressing drought and famine disasters in Puncak Regency. The activist emphasizes that the extremity of this region is not solely limited to the natural disasters it endures. Rather, it encompasses the conflicts and tensions that exist among different groups. In light of this, ensuring the safety and security of those providing support in the mountainous areas becomes crucial. The disability activist asserts that it is imperative for those offering assistance in these regions to be Papuans themselves. Their firsthand understanding of the dynamics and complexities of the area enables them to navigate the challenges more effectively. However, this requirement poses a significant challenge for PWDs in Papua Pegunungan, as they often find themselves in impoverished circumstances. Consequently, they become a burden on their families, especially during dire situations such as the current one.

The mountainous region of Papua is characterized by a combination of social, political, and environmental problems that are interconnected and characterized by a high degree of uncertainty. As a result, this context is marked by significant

disruptions. It is crucial to update the concept of human security in order to accurately capture this new reality. This necessitates moving beyond a narrow focus on the security of individuals and communities to also consider the interconnectedness among people and the planet, as emphasized in the 2030

Agenda for Sustainable Development (UNDP 2022). As a result, efforts to promote social inclusion must effectively address this complexity and possess the ability to adapt to the dynamic nature of the context.



YU leads his life as a farmer on a daily basis while he is engaged in clearing land for farming near the IDPs camp. Due to the armed conflict, he had to abandon his house, garden, and pigs in his village. Despite his loss of hearing, his dedication towards work remains unaffected. His sole aspiration is to have peace restored so that he can go back home.

As a consequence of the armed conflict that took place between 2018 and 2022, the region of Nduga has been designated as having a military emergency status, leading to the displacement of numerous residents across various areas, including Jayawijaya. Among those affected by this unfortunate situation are YU, along with his wife and four children, who are counted among the Nduga residents who were forced to leave their homes. The prevailing conditions of political instability

and security instigated their arduous journey from one place to another, as they sought safety and stability.

In their desperate bid to escape the impending danger, they were compelled to traverse through dense forests and treacherously steep mountain slopes, all while contending with challenging weather conditions. Throughout this arduous journey, they could not help but feel an overwhelming sense of sadness, as

they mourned the loss of several family members who tragically perished within the confines of the forest. The dire circumstances also witnessed the birth of several newborns among their fellow refugees, in a shocking display of life's resilience amidst the chaos and upheaval.

Prior to the outbreak of armed conflict, YU was engaged in farming, livestock rearing, and hunting activities within his place of origin. However, the eruption of violence and conflict forced him and his family to abandon their livelihoods and be separated from their loved ones. Eventually, they found themselves seeking refuge in Kuyawage, located within the Lanny Jaya Regency. During the span of a month spent there, they were compelled to continue their journey, eventually settling in Tiom, the capital of Lanny Jaya. After a week's stay in this new location, they resumed their arduous journey, finally arriving in Wamena, situated in the Jayawijaya Regency. It was in the village of Ilekma that they found solace, as they were able to establish a temporary home for more than a year.

Overall, the armed conflict that unfolded between 2018 and 2022 had profound and far-reaching consequences for the

region of Nduga. The military emergency status imposed in response to this conflict resulted in the displacement of thousands of residents, including YU and his family. The prevailing conditions of political instability and security compelled them to embark on a perilous journey, characterized by traversing dense forests, navigating treacherous mountain slopes, and braving challenging weather conditions. The emotional toll of the displacement was further exacerbated by the heartbreaking loss of family members and the unexpected arrival of newborns amidst the chaos. YU, who had previously relied on farming, livestock rearing, and hunting for sustenance, was forced to abandon his livelihood and be separated from his loved ones. Their journey ultimately led them to seek refuge in various locations, including Kuyawage and Tiom, before finding relative stability in the village of Ilekma. It is therefore evident that the armed conflict had a profound impact on the lives and well-being of the affected residents, necessitating comprehensive and sustained efforts to address their plight and facilitate their eventual return to a sense of normalcy.





IDPs come together, forming a collective, to connect on a deep level, sharing their personal narratives and experiences, providing solace and emotional support to one another, all the while engaging in activities that bring joy and amusement, such as crafting traditional net bags, which they skillfully create within the modest confines of their humble abodes. It is within these serene and cozy dwellings that an atmosphere of intimacy is cultivated, a safe haven where individuals can truly confide and express themselves, as they seek solace and comfort, knowing that they are not alone in their struggles. This deeply personal and nurturing environment serves as the sole means for fostering mutual resilience in the face of the profound anguish caused by conflict.

In August 2019, numerous riots occurred in various locations in Papua, including Wamena. These riots were initiated by racist remarks made towards Papuan students in Surabaya and other areas on the island of Java. When the chaos erupted, the students sought refuge in Pugima and stayed there for a month before returning to Ilekma. In 2020, they were relocated to a different area on the outskirts of the Jayawijaya region, based on an agreement between several tribal leaders. Although they realized they were no longer living on their ancestral land, they moved to the designated location and were grateful for the opportunity to reside there. They continue to inhabit this place without access to electricity, clean water, or proper sanitation facilities. Moreover, their knowledge regarding sanitation and hygiene is limited, posing a risk of bacterial infections and other illnesses.

As a person with disabilities living in challenging conditions like the internally displaced persons (IDPs) camps, YU encounters numerous obstacles in accessing basic services. These barriers can be economic, cultural, linguistic, or cognitive in nature, and they can also involve issues of trust. Generally, the IDPs from Nduga are very guarded due to the traumatic experience of violent conflict in their hometown, which resulted in the loss of their belongings and family members. Until now, they have not received any assistance in recovering from this trauma. They view any outsiders who visit their camp with suspicion, believing them to be spies from the TNI-POLRI intelligence. This mistrust is deeply ingrained in the entire community, from young children to adults. The only entities that have established close social connections with the IDPs community are the church and the local tribal leaders.

Unlike their children, who are able to speak Indonesian, YU and his wife are only able to communicate in their native language, Nduga. This poses significant challenges for them when attempting to interact with the larger community, as the majority of individuals in the area speak Hubula. In their daily lives, YU encounters even more difficulties due to his deafness, which restricts his ability to communicate effectively. As a result, he relies on his wife to communicate in Nduga or his children to serve as interpreters for those who speak Indonesian.

The journey from the camp where YU and his family reside to the Community Health Center, known as Puskesmas, is quite arduous. It takes approximately 1.5-2 hours to travel by foot or public transportation, which incurs additional transportation expenses. Since there are no health posts, or Pustu, available in the camp area for internally displaced persons (IDPs), they are forced to seek medical treatment at the Puskesmas. However, upon arrival, they are faced with the challenge of having to communicate in Bahasa Indonesia, despite not being fluent in the language. Unfortunately, there are occasions when the children, who have a better understanding of Indonesian, are left with no choice but to miss school in order to accompany their parents to the health center.

The administrative aspect of the Puskesmas is also crucial, particularly when dealing with individuals who are seriously ill and require referral letters. Unfortunately, YU and his family, along with other IDPs, are unable to fulfill these administrative requirements. This is primarily due to the fact that they have not been properly registered or do not possess a Family Card in their new place of residence. Because of this, they face

significant difficulties in accessing the necessary medical care and support.

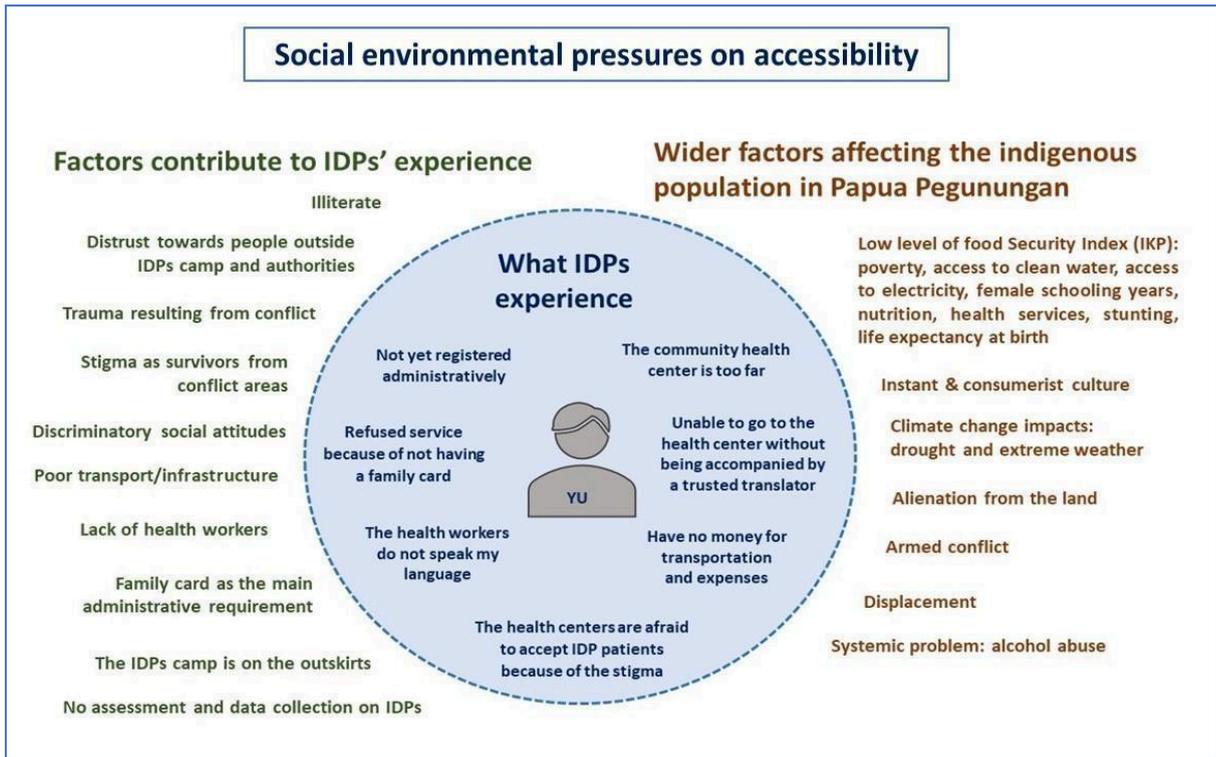
On the other hand, trauma experiences lead to a significant decrease in the level of trust that IDPs place in health workers, which can have a profound impact on their overall well-being. These internally displaced persons are constantly in a state of anticipation, eagerly searching for individuals whom they can truly rely on to act as a bridge between them and the understanding and access to essential health services that they so desperately require. It is worth noting that prior to YU becoming a person with a disability, he played a significant and reliable role within his family, as he was seen as a pillar of strength and respect within his community and clan in Nduga. Despite his illiteracy, YU's children greatly admire his remarkable skills in both farming and animal husbandry, which further highlights his value and contribution to their lives. Furthermore, YU actively served as a trusted village secretary in the village government, further emphasizing the high level of trust and respect that is bestowed upon him by his fellow community members.

However, as a result of becoming a disabled refugee, YU's entire world changed dramatically, as he suddenly found himself in a position of complete dependency on others for even the most basic of needs. Unfortunately, due to a multitude of obstacles that he and his wife have faced, such as language barriers, limited financial resources, and complex administrative processes, they have made the difficult decision to no longer seek treatment at a health service center. It is deeply distressing to witness the challenges and hardships that YU and his wife have had to endure, as they navigate a world that frequently fails to

accommodate and support persons with disabilities . Their story serves as a painful reminder of the urgent need for improved access to inclusive and empathetic healthcare services for all individuals, regardless of their circumstances.

YU's experience being an integral part of the system's resilience is of utmost importance. If we are to alter and modify YU's experience in terms of accessing health services, it is imperative that we actively promote and encourage a complete transformation of the entire system. By identifying and comprehending the various influential elements present within the system, we can gain a deeper understanding of the social and environmental pressures that have a significant impact on shaping and molding the experience of YU. It is crucial to recognize that YU's status as part of indigenous communities, as well as groups of persons with disabilities and IDPs, plays a pivotal role in influencing the relationship between YU and the larger system. Thus, there exist three distinct statuses that contribute to the framework of YU's relationship with the wider system. The resilience of the system itself is heavily influenced by the dynamics and interactions that exist within it. By acknowledging and carefully balancing the asymmetrical power relations present within these three status relations, we can effectively construct and develop a comprehensive transformation of the system as a whole.

There are numerous factors that directly contribute to shaping and influencing YU's experience as an IDP. As an individual with a disability who is living in poverty, YU faces a myriad of structural obstacles, such as the lack of social protection specifically designed for people with disabilities. Additionally, YU also encounters cultural barriers, such as the stigma and prevailing beliefs associated with disabilities. These challenges are similar to those faced by other study participants in Papua who also have disabilities, specifically individuals identified as YH. Furthermore, it is crucial to highlight that YU and YH's status as indigenous Papuans residing in the mountainous regions of Papua exposes them to a broader range of factors that have a profound impact on their overall well-being. In order to transform and enhance YU's experience, ensuring his access to basic services becomes a top priority. This necessitates an all-encompassing and comprehensive transformation of the system, one that safeguards and protects YU's basic rights as an individual with disabilities, IDPs, and as an indigenous Papuan living in highland Papua. Achieving this transformation and ensuring the well-being of YU calls for the implementation of integrated policies and interventions that address these specific needs and challenge.



Positive Deviance

In addition to addressing the ongoing challenges of insufficient sanitation and limited access to necessary services, which consistently present significant difficulties, refugees also confront the profound hardships of being deprived of opportunities for self-sufficiency and personal growth. Moreover, they frequently have to endure the persistent impact of trauma and the gradual erosion of trust in their fellow human beings. Individuals of all ages among conflict survivors, including vulnerable and innocent children, experience this trauma. The school principal explained that refugee children find a greater sense of comfort and security when they are in

groups, so they always walk together in groups to attend school. If one child is unable to attend, then none of the children will be able to go to school. YU's two young children are currently attending elementary school. These two individuals have been granted the opportunity to enter the educational institution without having to meet the usual administrative requirements. For the past three years, the school principal, EB, has taken great pleasure in warmly welcoming not only these two children, but also many other young people from the Internally Displaced Persons (IDPs) camp, and facilitating their active participation in the various educational activities offered by the school.



The children presently residing at the IDPs camp are actively engaging in the process of cartography to create a detailed map of their immediate surroundings, including the area where they currently reside. Each day, these resilient children undertake a challenging and demanding journey on foot, spanning a considerable distance of 1.5 to 2 hours, to reach their school from the IDPs camp. Previously, when they were in Nduga, these determined children used to make a similar hour-long journey on foot to reach their school.

The subsequent excerpt provides a vivid and detailed illustration of an exceptional occurrence that took place, showcasing a remarkable and extraordinary event that unfolded within the school system. It sheds light on the actions of the school principal who, in a truly commendable manner, decided to extend admission to refugee children, thus displaying a shining and awe-inspiring example of positive deviance. This particular incident serves as a powerful and impactful demonstration, underscoring the fact that the pursuit of fundamental rights extends far beyond the realm of mere bureaucratic requirements. It serves as a reminder that the school principal's decision represents a significant departure from the norm, as they went above and beyond to ensure that refugee children were given the opportunity to receive an education, thereby promoting inclusivity and equality within the educational system.

This remarkable act not only demonstrates the school principal's commitment to upholding fundamental rights but also serves as an inspiration and a testament to the potential for positive change within our society. It serves as a reminder that even in the face of bureaucratic challenges and constraints, it is possible to make a profound and lasting impact by prioritizing the well-being and rights of those who are often marginalized and overlooked. Overall, this exceptional occurrence exemplifies the power of individuals to effect change and highlights the importance of recognizing and celebrating positive deviance in our society. It serves as a call to action for others to follow in the footsteps of this remarkable school principal and to strive towards creating a more inclusive and equitable society.

The importance of the right to learn

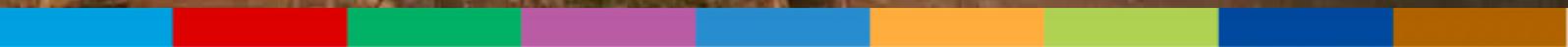
“I am absolutely thrilled that the children from the IDP camp have the incredible opportunity to receive an education at school. I warmly welcome them with open arms into our school, regardless of whether or not they possess a Family Card, because what truly matters above all else is their ability to read and write. Education should be a fundamental right afforded to all individuals, regardless of their location. It is true that these refugees may not have family cards, but what truly matters is that these children have the opportunity to attend school while we collectively ensure the well-being of their Family Cards. This is not just a mere policy, but a commitment to consider them an integral part of our community, and therefore, we should strive to eliminate any unnecessary obstacles that may impede their educational journey. Even though some of these children may not yet be fluent in Indonesian, they possess a remarkable understanding of the language. These remarkable kids are a true asset to our school, and we highly value them for their intelligence, wisdom, and remarkable aptitude. This is merely a matter of providing them with equal opportunities that they truly deserve.”

EB, school principal



CHAPTER 4

Study Implications





4. Study Implications

The results of the strategic review of documents and in-depth interviews have provided a detailed and thorough understanding of the complex and intricate structural landscape, shedding light on various crucial aspects. To begin with, it has become apparent that there is a deep interconnectedness between mindset, stigma, and the disability paradigm, which are all intertwined and influence one another. Urgent efforts are required to dismantle these mindsets, stigma, and disability paradigms, as they have a significant impact on how data is collected and analyzed, as well as on the development of governance tools, including regulations. The perpetuation of these mindsets and paradigms can lead to marginalization and discrimination, causing certain vulnerable groups to be completely overlooked and undetectable within the government system. Furthermore, it has been established that the quality of data and governance also play crucial roles in shaping this landscape, as they have the potential to either reinforce existing stigma and paradigms or challenge and transform them. It is essential to note that all of these interrelationships directly affect the realization of basic rights and the overall well-being of persons with disabilities. This highlights the utmost importance of addressing these factors comprehensively

and in a holistic manner in order to truly advance the rights and well-being of persons with disabilities.

Moreover, the examination of laws and policies has revealed a crucial finding. It has been observed that changes in laws alone, without being accompanied by a transformation towards a rights-based paradigm and contextual data, often render policies ineffective in safeguarding the rights of persons with disabilities. This highlights the importance of adopting a comprehensive approach that encompasses not only legal reforms but also a deep understanding of the rights-based perspective and the specific contextual factors that surround disability issues.

Lastly, the review has shed light on the need for translating the concept of inclusive development into tangible indicators that can capture the inherent complexity of the system. While the notion of inclusive development is widely acknowledged and embraced, it is essential to bridge the gap between theory and practice by establishing clear and measurable indicators. These indicators will serve as valuable tools for monitoring progress and ensuring meaningful participation from the groups affected by disability issues. By doing so,

we can truly advance towards a more inclusive society.

In the meantime, it is worth noting that the contextual landscape in West Sumba & Jayawijaya gives rise to a number of significant aspects that deserve our attention. Firstly, the interrelationship between various elements within the system, such as mindset, structure, and pattern of behavior, plays a crucial role in determining the level of accessibility that persons with disabilities have to basic services and opportunities to lead independent and dignified lives. This means that the way these elements interact with one another directly impacts the extent to which persons with disabilities can access the resources and support they need to live fulfilling lives.

Secondly, it is important to recognize that inclusion processes that fail to take into account non-economic indicators, including cultural context and social construction, such as gender, caste, and disability, are incapable of fully uncovering the underlying causes of persistent unequal opportunities. In other words, if we only focus on economic factors and disregard these other important aspects, we will not be able to fully understand why certain marginalized groups continue to face barriers and disadvantages.

Thirdly, it is crucial to acknowledge and address the main barriers that exist both horizontally and vertically, such as lack of trust towards authorities, social cohesion, and social protection. Only by recognizing and overcoming these barriers can we hope to break the vicious cycle that exists between disability and deprivation. It is not enough to simply address the immediate challenges that persons with disabilities face; we must also tackle the

deeper structural issues that perpetuate their marginalized status.

Lastly, by identifying positive deviance and understanding the social and environmental pressures that affect accessibility, we can gain valuable insights into the resilience of the systems in place and identify leverage points that can bring about positive change. This knowledge is particularly important when it comes to understanding the impact of these systems on marginalized groups, as it allows us to develop targeted interventions and strategies that address the specific needs and challenges faced by these individuals. It is clear that the contextual landscape in West Sumba & Jayawijaya offers a wealth of information and opportunities for us to improve the lives of persons with disabilities and promote greater inclusivity and equality.

The study implications encompass **two crucial components** that deserve utmost consideration. The initial element is located at the **contextual level or microscopic framework**, including bottom-up solutions within a system framework that has been carefully constructed by volunteers from the UN community. This framework is built upon the knowledge gained from immersive experiences in West Sumba and Jayawijaya. The diagram format illustrating these components can be found in the Appendix.

Meanwhile, the second component of this comprehensive framework encompasses various **strategic points of influence** that are of utmost importance and require undivided attention in order to effectively facilitate the transformation of the system towards achieving inclusive development. These strategic points of influence are not to be taken lightly, as they play a crucial

role in shaping the overall direction and outcome of the system transformation. In order to provide clear guidance and ensure smooth implementation, each strategic point of influence is accompanied by a well-thought-out rationale and a detailed operational guideline that is presented in an easily understandable diagram form. This approach allows for a comprehensive understanding of the underlying principles and strategies behind each strategic point of influence, enabling stakeholders to make informed decisions and take appropriate actions to drive the desired transformation and ultimately achieve inclusive development.

The results pertaining to the structural landscape and contextual assessment mentioned above generate strategic points of influence that can facilitate a comprehensive transformation of the system in order to attain inclusive development, thereby benefiting all individuals, including persons with disabilities who are part of marginalized communities in disadvantaged regions. These strategic points of influence consist of adopting a rights-based approach, utilizing warm data, ensuring meaningful participation of affected communities, recognizing the interconnectedness of social and environmental pressures, considering non-economic indicators, and implementing agile and adaptive governance.

UNCT's strategic steps to advance the status of the LNOB group

This study serves as a compelling demonstration of the utmost significance of engaging in integrated efforts when it comes to resolving intricate and multifaceted problems, all with the ultimate goal of attaining a genuinely inclusive development. It is crucial to acknowledge that integration goes far beyond mere technical coordination, as it delves into the realm of a profound integration of paradigms that are intrinsically intertwined with and guided by the UN's core values, particularly the concept of Human Rights-Based to Development (HRBD). It is of utmost importance to recognize that the United Nations Country Team (UNCT) occupies a pivotal and central position in the realm of safeguarding and promoting a rights-based approach within the United Nations and its various counterparts. To effectively advance this approach, it is imperative to prioritize and actively engage in activities such as raising awareness, fostering dialogue, and constructing impact measurement mechanisms, all of which can be accomplished by adopting and embracing the principles of HRBD. These agendas hold a significant level of importance and should be diligently pursued and upheld.

Adopting a rights-based approach

A human rights approach requires individuals and communities to be aware of their rights. Additionally, it implies that they are adequately supported in actively

participating in the formulation of policies and practices that have an impact on their lives, and also in asserting their rights whenever necessary. The Human Rights Based Approach (HRBA) is founded upon five fundamental principles of human

rights, commonly referred to as PANEL: Participation, Accountability, Non-discrimination and Equality, Empowerment, and Legality. In rights-based development, there are two key stakeholder groups—the rights holders (who do not fully experience their rights) and the duty bearers (the institutions obligated to ensure the realization of these rights for the holders). The rights-based approach strives to enhance the capabilities of duty bearers and empower the rights holders.

The process of involving horizontal parties in stages such as family and the surrounding environment, which has a direct impact on a person's inclusion or exclusion within the scope of family and society, is of great importance and is clearly demonstrated by the contextual assessment carried out in this study. This assessment not only emphasizes the significance of the two main parties involved, namely duty bearers and rights holders, but it also sheds light on the broader range of factors that play a role in determining a person's place in society. By taking into account the various parties involved and their interactions within the family and wider community, a much more comprehensive understanding of the concepts of inclusion and exclusion can be attained, thus enabling us to devise effective strategies for promoting inclusivity and reducing exclusionary practices.

The application of the rights-based approach on a large scale has the potential to bring about a transformative change in the mindset of justice for all. It has the remarkable ability to challenge and eliminate the deeply ingrained stigma and discrimination that often accompany societal attitudes towards certain groups or individuals. By embracing a

rights-based approach, a profound shift in societal perspectives can take place, leading to the creation of a more inclusive and equitable society that caters to the needs and rights of every individual, regardless of their background or circumstances. This approach holds tremendous promise in promoting social justice and fostering an environment where everyone can fully participate and thrive.

In addition to addressing issues of stigma and discrimination, the rights-based approach also opens up dialogue regarding governance. Currently, disability issues are often categorized under social issues, falling under the jurisdiction of the Ministry of Social Affairs, rather than being recognized as discrimination issues. By engaging in conversations surrounding governance, the relevant parties, including the UN, government, law enforcement, national commission for persons with disabilities, organizations of persons with disabilities, and other related institutions, can work together to redefine the understanding and treatment of disability issues.

To effectively implement a rights-based approach, it is crucial to have collaboration across various media and platforms. This collaboration is of utmost importance as it ensures that all aspects of the approach are integrated seamlessly. This integrated approach encompasses a wide range of activities that work together to achieve the desired outcomes. These activities begin with raising awareness among individuals and communities, ensuring that they have a clear understanding of their rights. Additionally, knowledge management plays a significant role in this approach, as it allows for the effective dissemination of information and the sharing of best

practices. Furthermore, the development of technical skills is essential in order to translate this understanding into actual behavioral patterns. This requires individuals to have the necessary expertise and capabilities to apply their knowledge in practical ways.

Moreover, the implementation of a rights-based approach also involves the establishment of legal rules, budgeting, and policies that uphold the principles of inclusion and non-discrimination. These legal rules are the foundation upon which the approach is built, ensuring that all individuals are treated fairly and equitably. Budgeting is also a critical aspect of this approach, as it ensures that the necessary resources are allocated to support the implementation of various initiatives. Additionally, policies play a significant role in guiding the decision-making process and ensuring that the approach is aligned with the principles of inclusion and non-discrimination.

Furthermore, the strengthening of institutional structures is essential in supporting the implementation of a rights-based approach. These structures provide the necessary framework and support for the various activities and

initiatives that are part of the approach. They ensure that there is a clear and coordinated effort in place, and that the approach is effectively implemented at all levels. By strengthening these structures, the overall effectiveness of the approach is enhanced, leading to better outcomes for individuals and communities.

By engaging in these activities and considering all these aspects, a comprehensive and holistic rights-based approach can be achieved. This approach ensures that individuals are empowered and that their rights are respected and protected. It provides a framework for addressing various issues and challenges, and it promotes a culture of inclusivity and non-discrimination. Through collaboration, knowledge sharing, and the establishment of legal rules and policies, the implementation of a rights-based approach becomes a collective effort that benefits everyone. It allows for the translation of understanding into action, and it creates a more just and equitable society. Therefore, it is imperative to recognize the importance of collaboration and the various elements that contribute to the effective implementation of a rights-based approach.

Adopting a rights-based approach



Utilizing Warm Data

In the broad perspective of things, data ecosystems should effectively and comprehensively implement the guiding principles of the Human Rights-Based Approach to Data (HRBAD), which are fundamentally rooted in ensuring inclusivity, engagement, and empowerment of all individuals involved. These principles encompass various pivotal aspects, including but not limited to active participation of all stakeholders, meticulous data disaggregation to capture the diverse characteristics and needs of different groups, the significant recognition and respect for individuals' self-identification, utmost transparency in data processes and systems, safeguarding privacy rights, and ensuring appropriate and just accountability mechanisms are in place to address any potential issues or violations that may arise.

Complexity, which is a concept that encompasses various intricate and

interrelated aspects, cannot be fully comprehended, or analyzed using only a single methodology or approach. Rather, a more comprehensive understanding of the system as a whole, including both its overarching dynamics and its granular components, can be achieved through the utilization of mixed methods. By employing a combination of different approaches, stakeholders and analysts can gain insights into the multifaceted nature of the system, exploring it from both a macroscopic viewpoint, encompassing the broader context and overarching patterns, as well as a microscopic perspective, which delves into the specific elements that exert influence on the resilience of the system.

When it comes to delving into the depths of investigating structural inequalities within the system, statistical methods present themselves as an invaluable and indispensable tool, providing an opportunity to unveil, expose, and

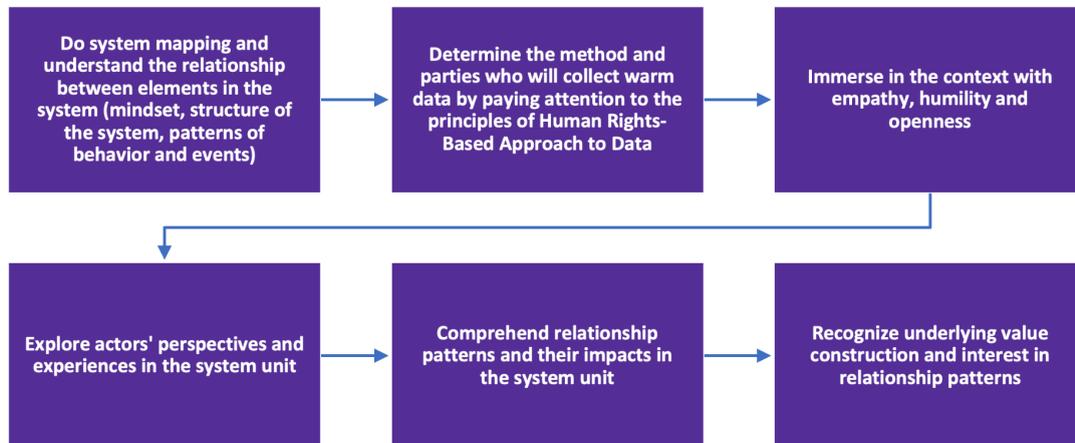
decipher patterns and trends that lie beneath the surface. By employing the employment of statistical analyses, we are equipped with the means to meticulously examine, scrutinize, and interpret data in order to effectively identify, recognize, and comprehend the existence and implications of these structural inequalities that pervade our society. Moreover, the utilization and application of big data, characterized by its vast magnitude and scope, opens up a whole new realm of possibilities, providing us with a promising avenue for exploring, investigating, and discerning intricate patterns and relationships that exist within complex systems. Through the astute harnessing, wielding, and utilization of the immense power and potential that lies within vast amounts of data, we are able to skillfully uncover, reveal, and bring to light hidden connections and correlations, thus enabling us to attain, achieve, and acquire a more profound, enlightened, and nuanced understanding of the intricate and multifaceted dynamics at play within our society.

However, it is important to recognize that there are certain aspects of the system that cannot be fully understood or elucidated through traditional statistical methods or big data analysis alone. Specifically, relationship patterns that arise from imbalanced social relations and contribute to social exclusion require a different approach. In this regard, the concept of warm data comes into play. Warm data refers to a methodology that focuses on understanding the complexities of social interactions and the underlying

dynamics that perpetuate imbalances and exclusions. By employing warm data analysis, we can delve into the intricacies of social relationships, uncovering the nuances and intricacies that may not be captured by traditional methods. This enables a deeper comprehension of intersectionality within the social inclusion process.

The utilization of warm data in the analysis of social systems presents a significant opportunity to gain valuable insights into the various indicators and factors that contribute to imbalances and inequalities at multiple levels of the system. Through the acquisition of a comprehensive understanding of these indicators, stakeholders and interested parties, such as policymakers, have the ability to develop interventions and design policies that are not only relevant, but also effective and sustainable in addressing these imbalances and inequalities. This approach, known as a contextual assessment of the system, allows for a more nuanced and holistic understanding of the complexities at hand. By having this comprehensive view, stakeholders are empowered to make well-informed decisions and take appropriate actions in order to address these imbalances and inequalities. Consequently, the adoption of a contextual assessment approach plays an integral and crucial role in effectively navigating the intricacies of complex systems and ultimately promoting a society that is more inclusive and equitable.

Utilizing warm data



Ensuring meaningful participation of affected communities

The initial step in the process of deep listening to systems involves the implementation of a contextual assessment, which serves to generate warm data. Through the conduct of a comprehensive contextual assessment, one can acquire a holistic understanding of the various components present within the system. This understanding enables the facilitation of PWDs and other marginalized groups in their pursuit of accessing and exercising their fundamental rights. Moreover, the examination of the socio-cultural context that surrounds these individuals is of utmost importance in order to formulate appropriate plans for effectively engaging the affected communities within their respective contexts.

For instance, indigenous women who find themselves residing in a state of impoverishment and confronting physical

impairments are frequently subjected to exclusion from the realm of the family due to the prevailing cultural context that favors male dominance. To ensure the successful involvement and active participation of this specific group, it is absolutely crucial for the strategy of engagement to fully acknowledge the multitude of diversities that exist within the given context, encompassing various factors such as gender identity, specific types of disabilities, familial circumstances, societal norms, and effective modes of communication. By meticulously considering and addressing these intricate aspects, the actualization of genuine and meaningful participation can truly be achieved. This fundamental principle of inclusivity and comprehensive engagement can also be effectively applied to other marginalized groups facing similar challenges and forms of exclusion.

Hence, it is of utmost importance to actively engage and involve the affected communities throughout the entirety of

the process, rather than treating them merely as passive recipients or mere checkboxes to be ticked off. A notable example of implementing this principle is through the integration of United Nations community volunteers, who themselves belong to the affected groups, in conducting comprehensive contextual assessments. This approach ensures a profound and empathetic understanding of the complex systems at play, aligning with the principles of Leave No One Behind (LNOB) and simultaneously promoting a Human Rights-Based Approach to Development (HRBD).

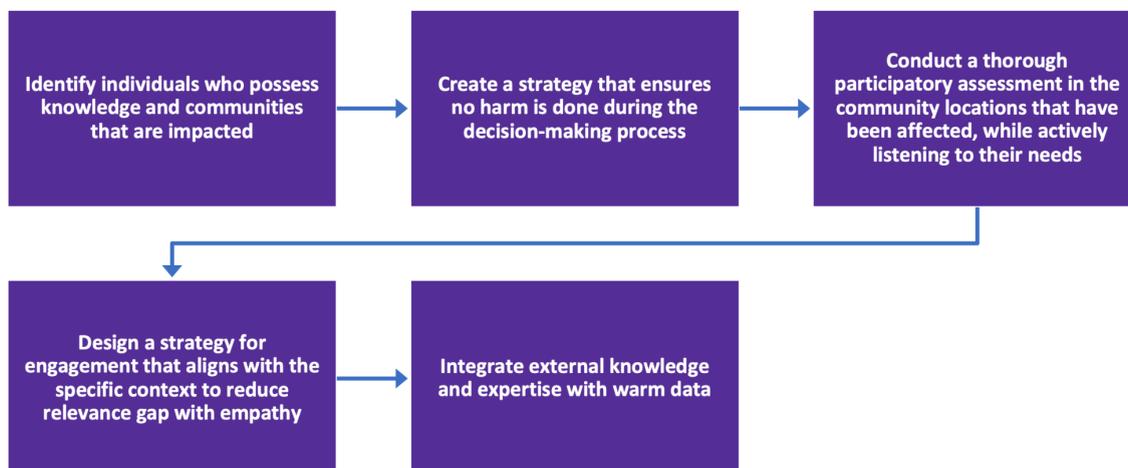
Meaningful participation extends beyond mere physical presence; it is the outcome of combining external knowledge and expertise (etic) with insider perspectives and experiences from the end user (emic). This particular approach not only bridges the gap of relevance with affected communities, but also showcases a higher degree of sensitivity and empathy towards the context in which these communities are situated. To truly address issues of inequality and justice, it is essential to step outside the confines of luxurious five-star hotels and engage in discussions in a more accessible and inclusive setting. This perspective is evident in the participation patterns of affected communities throughout the entire process, ranging from the initial stages of planning to the implementation of activities that are related to the objective of Leaving No One Behind (LNOB).

Meaningful participation should also be conducted during the process of collecting data by implementing a Human Rights Based Approach to Data (HRBAD). For instance, the requirement for disability certificates does not align with one of the

principles of HRBAD, which highlights the importance of self-identification. In accordance with this principle, populations of interest should have the ability to define themselves when it comes to data collection. Individuals should have the freedom to choose whether to reveal or withhold information about their personal characteristics. Another principle of HRBAD, which emphasizes the involvement of relevant population groups in data collection exercises, suggests that disability organizations should be authorized to issue disability certificates. These organizations possess the necessary expertise concerning various types of disabilities and the associated needs, including access to assistive devices.

Through the promotion of meaningful participation from affected communities, the process of social change becomes dignified and instills a strong collective sense of belonging. Consequently, it is imperative for the individuals entrusted with the task of designing interventions and policy programs, such as renowned international organization like the United Nations, reputable academic institutions, influential governmental bodies, and other esteemed organizations dedicated to fostering meaningful participation and facilitating organic social change, to possess the requisite set of skills that enable them to engage in deep listening to systems. These skills play an indispensable role in fostering a transformative approach that not only empowers marginalized communities but also propagates the notion of inclusive development by ensuring that the voices of all stakeholders are heard and taken into earnest consideration.

Ensuring meaningful participation of affected communities



Recognizing the interconnectedness of social and environmental pressures

In the present era of the climate crisis, there is a clear and unmistakable realization that the various aspects of social ecology are intricately interwoven and cannot be disentangled. It is an undeniable and irrefutable truth that human behavior, encompassing the products and actions of policies, exerts a profound and far-reaching influence on the overall well-being of the earth and all its inhabitants. One simply cannot disregard or overlook the fact that social exclusion, which manifests itself as imbalanced social relationships, is intimately and closely linked to the issue of planetary pressures.

When considering the structure of system transformation, the idea of social inclusion covers a wide range and variety of different factors, including not only the social aspects but also the environmental ones. All of these elements have a substantial influence on the ability of

systems to withstand and adjust to challenges. These elements include, but are not limited to, armed conflicts, the consequences and repercussions of the climate crisis such as extreme weather events, systemic issues within a given context, cultural practices, and values that perpetuate and sustain persistent and enduring inequality, among a myriad of others.

The disruption of the system will undoubtedly have a significant impact on the accessibility and fulfillment of the basic rights of persons with disabilities and other marginalized groups. In order to effectively address this situation, it is of utmost importance to carefully strategize and implement intervention programs and policies that embrace a comprehensive and holistic systems thinking approach.

In order to effectively address this situation and devise an optimal solution, it is imperative to meticulously devise and execute well-thought-out intervention programs and policies that

wholeheartedly embrace and encompass a comprehensive and all-encompassing systems thinking approach. This approach entails considering and analyzing the interconnectedness and interdependencies of various components within the system, both internal and external, and recognizing the intricate relationships and dynamics between them. By adopting such a holistic perspective, decision-makers can gain a deeper understanding of the complexities and intricacies of the situation at hand, enabling them to identify and address the root causes of the problem rather than merely treating the symptoms.

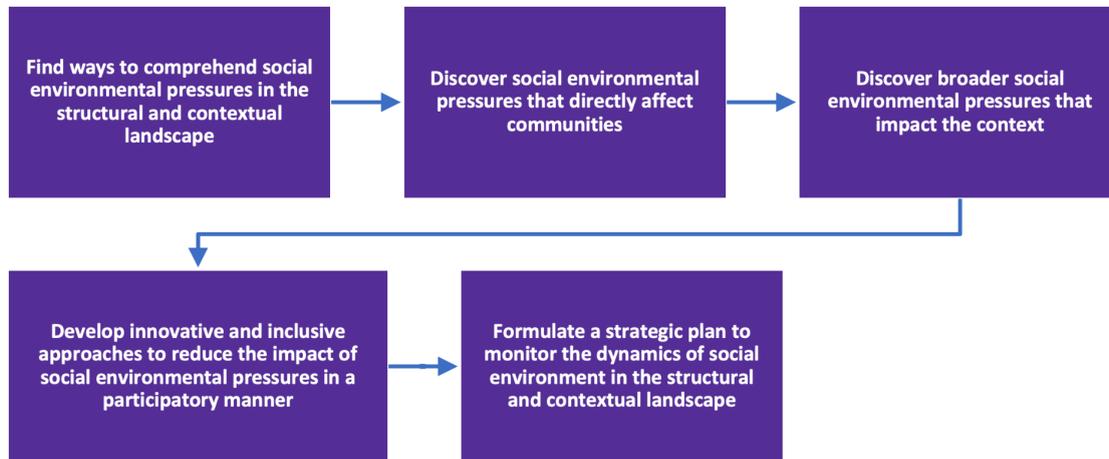
Furthermore, this approach encourages a multidimensional and interdisciplinary viewpoint, encouraging collaboration and cooperation between various stakeholders and experts from different fields and backgrounds. Through this collaborative effort, diverse perspectives and expertise can be brought together, fostering innovative and effective solutions that can yield long-lasting and sustainable outcomes. Additionally, by considering the system as a whole, rather than focusing on individual components in isolation, decision-makers can anticipate and mitigate potential unintended consequences and negative feedback loops that may arise from their interventions.

This proactive and forward-thinking approach can help prevent future issues and ensure the stability and resilience of the system in the face of potential disruptions or shocks. In conclusion, to effectively address the situation at hand, it is essential to adopt a comprehensive and holistic systems thinking approach, which involves carefully strategizing and implementing intervention programs and policies that take into account the

interconnectedness and interdependencies of the system's various components, promote multidimensional collaboration and cooperation, and anticipate and mitigate potential unintended consequences. By adopting this particular method, both individuals and organizations have the ability to skillfully maneuver through the complex and intricate aspects that invariably emerge in these circumstances, encompassing, but not restricted to, volatility, uncertainty, complexity, and ambiguity, widely recognized as the acronym VUCA. Through the implementation of this purposeful and reflective approach, the ultimate goal of achieving a profound and beneficial transformation within the system can be effectively accomplished.

The outcome that arises from the presence of these particular parameters is the emergence and establishment of interventions and policies that extend over a lengthy period of time and encompass various sectors, thereby transcending the boundaries and limitations imposed by a narrow focus. It is crucial to recognize that in order to successfully confront and tackle the multifaceted difficulties and obstacles posed by the existing climate emergency, it is imperative to engage in a collaborative and integrated manner, as this becomes an unavoidable prerequisite. It is only through the adoption and implementation of such all-encompassing and comprehensive approaches that we will be able to effectively and efficiently confront the numerous challenges presented by the ongoing climate crisis and simultaneously safeguard and uphold the well-being and fundamental rights of every single individual, with a particular emphasis on those who find themselves marginalized and vulnerable.

Recognizing the interconnectedness of social and environmental pressures



Considering non-economic indicators

The concept and attainment of well-being as well as the achievement of a good quality of life are deeply impacted by a combination of knowledge, personal experiences, and the construction of societal norms. This influence becomes even more significant and relevant within the distinctive context of Indonesia, a nation renowned for its remarkably rich and diverse cultural heritage. In order to ensure the sustenance of a harmonious equilibrium within social and ecological relationships, it is of utmost importance to prioritize and acknowledge the wide range of values present within society. This emphasis on diversity should be given utmost consideration and placed at the forefront of the formulation of policies and implementation of programs.

It is important to take note of the fact that indigenous peoples, who have their own unique and distinct set of values that have

been passed down from one generation to another, often find themselves in a situation where they are faced with external value systems and orders that are imposed on them. These external value systems and orders are often associated with modern development and the parameters that come with it. In order to address this particular challenge, it becomes necessary to integrate parameters and considerations from multiple perspectives. One possible approach to do this could be to combine biodiversity considerations within the realm of food security. This would involve taking into account the importance of biodiversity in ensuring food security for indigenous communities. Additionally, it would also be beneficial to consider modern economic valuation in this integration process. This means taking into consideration the economic value associated with biodiversity and how it contributes to the overall well-being of indigenous communities. Furthermore, it

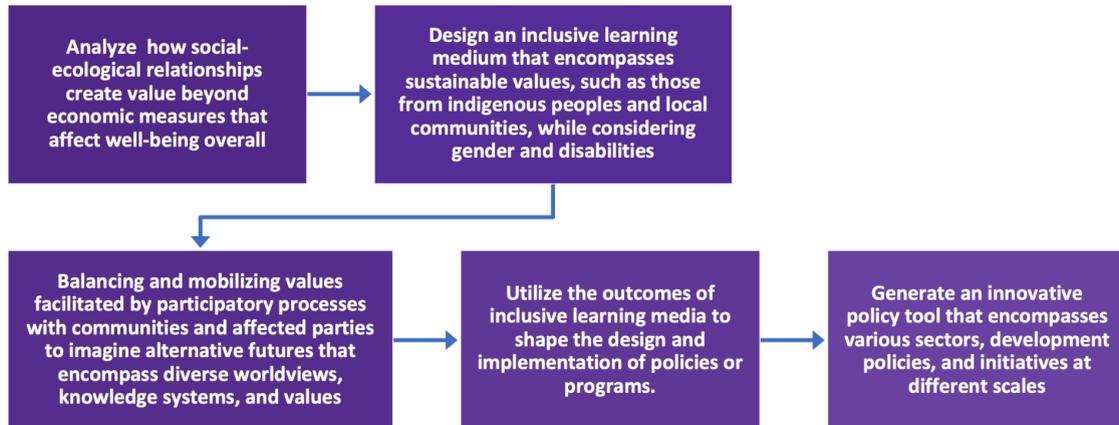
would be advantageous to adopt a cultural resilience framework that is capable of promoting and preserving biocultural diversity resilience. This framework would take into account the cultural aspects of indigenous communities and how they are intertwined with the natural environment. Finally, this approach would also involve accommodating non-economic indicators within the valuation process. This means recognizing and valuing the non-economic contributions of indigenous communities to the overall well-being of society.

It is essential to recognize that inclusive development extends beyond the realm of individual well-being. It also entails creating space and providing opportunities for a wide range of value evaluations that collectively shape and define the overall quality of life experienced by individuals and communities. Therefore, according to the findings and recommendations put forth by the Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services (IPBES) in 2022, it is imperative to adopt policies that are centered on values. These policies should not only recognize and acknowledge the existence of diverse

values, but also strive to strike a balance between these values. Simultaneously, they should also address and mitigate existing social and economic inequalities among various actors within society.

Values-centered policies are deeply rooted in the understanding that values are not innate or fixed, but rather are constructed and embedded within complex knowledge systems, diverse languages, rich cultural traditions, and the intricate environmental contexts that shape our lives. These policies recognize and fully embrace the multifaceted nature of how individuals and communities interact with one another and with the natural world, acknowledging that these relationships are dynamic and ever-evolving. In order to effectively promote and achieve sustainability-aligned values, it is absolutely essential to proactively and intentionally take into consideration and accommodate a wide range of non-economic indicators that encompass various dimensions of human well-being and ecological health. These proactive initiatives serve as strategic and forward-thinking actions that are aimed at realizing a sustainable and harmonious future for all.

Considering non-economic indicators



Implementing agile and adaptive governance

In this epoch, which is marked by the presence of forces that disrupt and create disorder, it becomes incredibly clear and undeniable that there is an immediate requirement for governance that is both agile and adaptive. This is due to the fact that the world is currently facing urgent and pressing issues, such as the climate crisis and the levels of inequality that have reached unprecedented heights. When we speak of agile governance, we are referring to a primary area of concentration that encompasses a wide array of working practices and methodologies. These practices and methodologies are specifically designed to efficiently facilitate and enable prompt reactions and responses to the challenges and obstacles that arise. On the contrary, adaptive governance possesses a distinguishing feature in its ability to efficiently handle and maneuver intricate societal problems that encompass a multitude of individuals or groups with differing objectives and a prevailing sense

of doubt or vagueness surrounding the most suitable path to be pursued. An example of such a complex issue is the intricate matter of relocating a community in response to the challenges brought about by climate change.

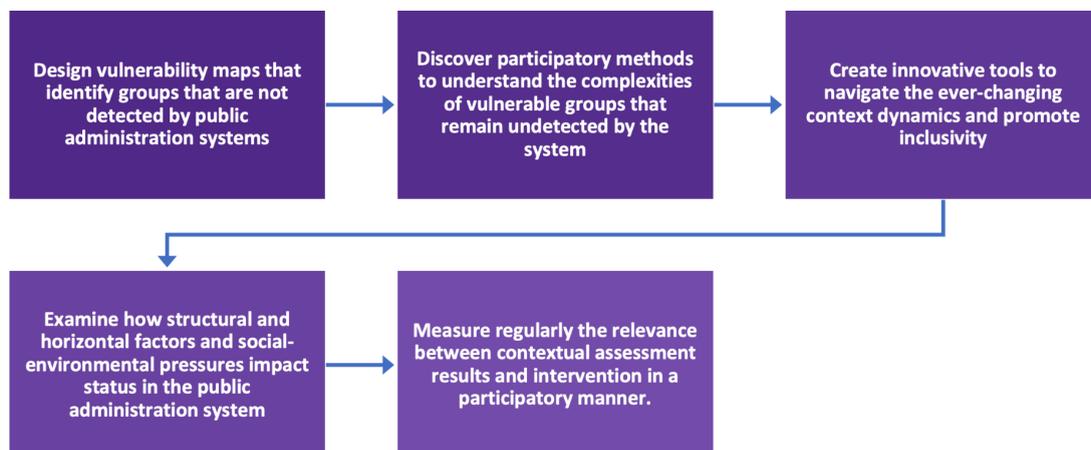
The incorporation and application of agility and adaptability within the domain of governance is firmly grounded in the fundamental tenets of development that are centered around the principles of rights-based growth, thereby ensuring that both the act of taking part in the decision-making processes and the advantages arising from the progress of society are encountered inclusively by every single member of the community. By faithfully adhering to these principles, bureaucratic and governance structures that possess the qualities of being agile and adaptive are able to seamlessly incorporate and assimilate individuals hailing from all walks of life into their systems, thereby ensuring that no one is left behind or excluded. Moreover, such structures are equipped with the

capability to deliver public services in a manner that is not only easily accessible to the general populace but also aligns with the unique circumstances and requirements of each individual citizen, taking into account various factors such as the social milieu within which they reside, the prevailing environmental conditions, as well as any disabilities they may have.

This indicates that the agile and adaptive form of governance showcases an exceptional and noteworthy capability to navigate through and triumph over a wide range of unexpected and unforeseen disruptions and obstacles that may occur within the previously mentioned contexts. These contexts encompass a variety of scenarios such as natural calamities related to the climate, instances of

conflicts, and diverse categories of disabilities. The importance of this capacity cannot be overstated as it lies at the core of the pursuit of ensuring the protection and well-being of all individuals who are recipients of development initiatives. Specifically, it places significant emphasis on addressing the needs and concerns of vulnerable groups who reside in areas that are marked by various forms of disadvantages. By embracing an approach to governance that is both agile and adaptive, society can take preemptive measures to effectively tackle and diminish the adverse effects of these challenges. As a result, this can foster a future that is characterized by fairness, equality, and inclusiveness for every member of society.

Implementing agile and adaptive governance



Appendix



Appendix

Bottom-up Solutions



Lack of knowledge & understanding about the rights of PWDs

CAUSATIVE FACTOR



WHAT

Impairment rather than disability



HOW

Disability is related to customary issues and the consequences of conflict and violence



WHY

Ignorance, indifference, no socialization, no data collection and no supporting programs

IMPACT



ACCESSIBILITY

- Distrust of modern health services
- No sign language education
- PWDs have not really demanded their rights from the government (village and regional government, social services, and health)
- No psychosocial support for PWDs at IDPs camp



MISSED OPPORTUNITY

- Missed job, good communication
- Expanding social environment
- Social involvement (customs, village government, public worship)
- Visiting relatives
- Ensuring kinship



RISK

- Loss of space for self-expression and livelihood
 - High psychological pressure on PWDs
 - Family breakdown
 - Additional economic burden for children and partners
- Needs of PWDs not being accommodated by local government



Low trust towards authority

CAUSATIVE FACTOR



WHAT

No solutions and failure to comply with agreements in meeting PWDs needs



HOW

Do not receive social protection (PKH) and other social assistance



WHY

The relationship gap between village and regional governments, misuse of data on PWDs, carelessness and inability to capture and manage community aspirations, do not prioritize PWDs

IMPACT



ACCESSIBILITY

- Absence of information regarding village activities
- Local legal products/regulations that support PWDs and basic services (health and education)



MISSED OPPORTUNITY

- Participating in village activities, decision-making processes, self-expression



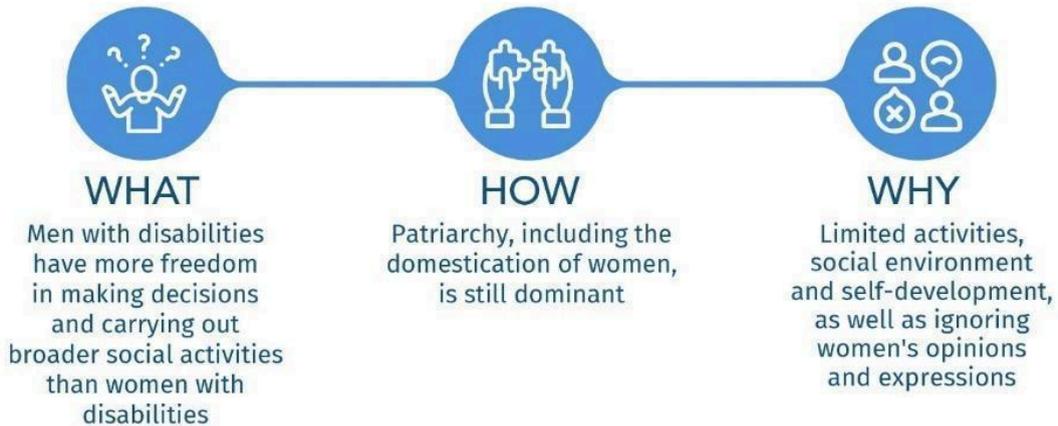
RISK

- Neglected from village activities and assistance from the government (such as PKH) as well as loss of government employment opportunities



Lack of gender perspectives

CAUSATIVE FACTOR



Bottom-up solutions to strengthen knowledge and understanding of the rights of people with disabilities, levels of trust in authority and gender values

SYSTEM UNIT	Needs	Resources (material & non material)	Capability	Relations / Collaboration
Family	Communication support, socialization about the right of PWDs	Hearing aids and inclusive communication media including for illiterate and non native speakers	Improved educational level	Improved relations within nuclear family to provide access for women with disabilities, better support from extended family, better trust in others outside IDPs camp
Neighborhood	Support from adat, the church & local government, empathy & trust towards PWDs	Socialization about PWDs right self-development tools (e.g. farming or gardening)	Knowledge & education	Collaboration between community neighborhood & social services
Village Government	Support from adat leaders & data collection on PWDs	Alignment of thought between adat & government, physical & psychological support for PWDs	Ability to listen & capture the needs of community & PWDs, ability to understand & support the rights of PWDs	Collaborative monitoring with BRILink (appointed agent of a government bank), collaboration with village head, church and adat
Local Government Unit (Dinas)	Support for companions for PWDs, data (initial information)	Budget support for field visits	Qualified PWDs companions & local community facilitators	Collaboration with family, neighborhood, social & health services unit
Health Services	Data on PWDs & special health services for PWDs	Family openness, health posts near settlements with health workers who can speak the local language	improved health service, good understanding about local language, culture & social psychology	Collaboration between village government, social services unit & family
Educational Services	Sign language & Bahasa Indonesia	Hearing aids, sign language learning materials & tutors	Sign language	Family, schools, education & social services unit

CRPD Recommendations

Recommendation	Human rights themes and groups of persons	Relevant SDGs
Theme: Ratification of & accession to international instruments		
Work towards ratification of the Convention on the Rights of Persons with Disabilities in consultation with national stakeholders and in line with national priorities	<ul style="list-style-type: none"> - Ratification of & accession to international instruments - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	- 16 - PEACE, JUSTICE AND STRONG INSTITUTIONS
Theme: Equality & non-discrimination		
Uphold the rights to freedom of expression, assembly and religion or belief, prevent discrimination on any grounds, including disability, sexual orientation, gender identity and intersex status, and enhance efforts to reduce violence against women and girls	<ul style="list-style-type: none"> - Equality & non-discrimination - Violence against women - Freedom of thought, conscience & religion - Right to peaceful assembly - Members of minorities - Freedom of opinion and expression & access to information Groups of Persons: <ul style="list-style-type: none"> - Lesbian, gay, bisexual and transgender and intersex persons (LGBTI) - Women & girls - Minorities/ racial, ethnic, linguistic, religious or descent-based groups - Persons with disabilities 	<ul style="list-style-type: none"> - 5 - GENDER EQUALITY - 10 - REDUCED INEQUALITIES - 16 - PEACE, JUSTICE AND STRONG INSTITUTIONS
Continue to strengthen the protection of vulnerable groups, especially older persons and persons with disabilities	<ul style="list-style-type: none"> - Equality & non-discrimination - Persons with disabilities: definition, general principles - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Older persons - Vulnerable persons/groups - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Continue ensuring the protection of the rights of women, children, persons with disabilities and older persons	<ul style="list-style-type: none"> - Equality & non-discrimination - Persons with disabilities: definition, general principles - Children: definition; general principles; protection - Discrimination against women - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Children - Older persons - Women & girls - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Continue its efforts to develop effective legislative measures to protect and	<ul style="list-style-type: none"> - Equality & non-discrimination - Legal & institutional reform - Persons with disabilities: definition, general principles 	- 10 - REDUCED INEQUALITIES

promote the rights of the elderly and persons with disabilities	<ul style="list-style-type: none"> - Constitutional & legislative framework - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Older persons - Persons with disabilities 	
Continue efforts to ensure the full implementation of initiatives to promote and protect the rights of persons with disabilities and older persons	<ul style="list-style-type: none"> - Equality & non-discrimination - Persons with disabilities: definition, general principles - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Older persons - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Implement effective policies and programmes to ensure the enjoyment of human rights by older persons and persons with disabilities	<ul style="list-style-type: none"> - Equality & non-discrimination - Persons with disabilities: definition, general principles - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Older persons - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Support mechanisms and programmes aimed at accelerating the realization of human rights for vulnerable groups, especially women, children and persons with disabilities	<ul style="list-style-type: none"> - Equality & non-discrimination - Persons with disabilities: definition, general principles - Children: definition; general principles; protection - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Children - Vulnerable persons/groups - Women & girls - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Theme: Right to development		
Redouble efforts to narrow the socioeconomic development gap between urban and remote areas	<ul style="list-style-type: none"> - Right to development - Equality & non-discrimination - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Persons living in rural areas 	- 10 - REDUCED INEQUALITIES - 16 - PEACE, JUSTICE AND STRONG INSTITUTIONS
Theme: Human rights & climate change		
Implement inclusive policies to prevent and address the negative impacts of climate change and reduce disaster risk, especially for vulnerable people or minorities living in remote areas	<ul style="list-style-type: none"> - Human rights & climate change - Economic & political crisis, natural disasters or other emergencies Groups of Persons: <ul style="list-style-type: none"> - Persons living in rural areas - Vulnerable persons/groups - Minorities/ racial, ethnic, linguistic, religious or descent-based groups 	- 1 - NO POVERTY - 11 - SUSTAINABLE CITIES AND COMMUNITIES - 13 - CLIMATE ACTION
Theme: Right to health		
Intensify efforts to reduce the incidence of maternal mortality, especially in rural areas	<ul style="list-style-type: none"> - Right to health Groups of Persons: <ul style="list-style-type: none"> - Persons living in rural areas - Women & girls 	- 3 - GOOD HEALTH AND WELL-BEING

Take further steps to support persons with mental health conditions and disabilities	<ul style="list-style-type: none"> - Right to health - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	- 3 - GOOD HEALTH AND WELL-BEING
Continue the implementation of the national programme for medical assistance for persons in need in remote areas throughout the country	<ul style="list-style-type: none"> - Right to health - National Human Rights Action Plans (or specific areas) / implementation plans Groups of Persons: <ul style="list-style-type: none"> - Persons living in rural areas 	- 3 - GOOD HEALTH AND WELL-BEING
Improve the coverage and quality of essential health services, especially for groups in situations of poverty and persons living on small, remote islands and in the eastern provinces	<ul style="list-style-type: none"> - Right to health - Human rights & poverty - Right to an adequate standard of living Groups of Persons: <ul style="list-style-type: none"> - Persons living in poverty - Persons living in rural areas 	- 3 - GOOD HEALTH AND WELL-BEING

Theme: Sexual & reproductive health and rights		
Ensure that comprehensive sexual and reproductive health education is included in the national education curriculum, including for women and girls with disabilities	<ul style="list-style-type: none"> - Sexual & reproductive health and rights - Persons with disabilities: definition, general principles - Right to health - Right to education Groups of Persons: <ul style="list-style-type: none"> - Women & girls - Persons with disabilities 	- 3 - GOOD HEALTH AND WELL-BEING - 4 - QUALITY EDUCATION - 5 - GENDER EQUALITY
Theme: Discrimination against women		
Strengthen measures taken to eliminate discrimination against women and girls with disabilities	<ul style="list-style-type: none"> - Discrimination against women - Equality & non-discrimination - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Women & girls - Persons with disabilities 	- 5 - GENDER EQUALITY
Theme: Violence against women		
Take all necessary measures to ensure the effective implementation of programmes on combating violence against women, reducing maternal mortality and improving access to reproductive health-care services, especially in rural and remote areas	<ul style="list-style-type: none"> - Violence against women - National Human Rights Action Plans (or specific areas) / implementation plans - Right to health - Sexual & gender-based violence - Sexual & reproductive health and rights Groups of Persons: <ul style="list-style-type: none"> - Persons living in rural areas - Women & girls 	- 3 - GOOD HEALTH AND WELL-BEING - 5 - GENDER EQUALITY

Theme: Persons with disabilities: definition, general principles		
Intensify efforts to guarantee the fulfilment of the rights of persons with disabilities	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Continue to increase efforts to promote employment of people with disabilities	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles - Labour rights and right to work Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	<ul style="list-style-type: none"> - 8 - DECENT WORK AND ECONOMIC GROWTH - 10 - REDUCED INEQUALITIES
Strengthen the role of the National Commission on Persons with Disabilities to address the challenges which people with disabilities may face	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles - Legal & institutional reform Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	<ul style="list-style-type: none"> - 10 - REDUCED INEQUALITIES - 16 - PEACE, JUSTICE AND STRONG INSTITUTIONS
Continue its ongoing efforts to address various challenges in fully implementing the rights of persons with disabilities through national complaint mechanisms	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Continue to strengthen the implementation of the National Action Plan on Persons with Disabilities	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles - National Human Rights Action Plans (or specific areas) / implementation plans Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	- 10 - REDUCED INEQUALITIES
Continue efforts to accelerate the integration of disability issues into the national development agenda	<ul style="list-style-type: none"> - Persons with disabilities: definition, general principles Groups of Persons: <ul style="list-style-type: none"> - Persons with disabilities 	<ul style="list-style-type: none"> - 10 - REDUCED INEQUALITIES - 17 - PARTNERSHIPS FOR THE GOALS
Theme: Persons with disabilities: independence, inclusion		
Develop an inclusive education strategy for children with disabilities at the national, provincial and local levels, covering all levels of education	<ul style="list-style-type: none"> - Persons with disabilities: independence, inclusion - National Human Rights Action Plans (or specific areas) / implementation plans - Right to education Groups of Persons: <ul style="list-style-type: none"> - Children - Persons with disabilities 	- 4 - QUALITY EDUCATION
Take all necessary measures to ensure an inclusive learning environment for children with disabilities, including by increasing	<ul style="list-style-type: none"> - Persons with disabilities: independence, inclusion - Right to education Groups of Persons: <ul style="list-style-type: none"> - Children - Persons with disabilities 	<ul style="list-style-type: none"> - 4 - QUALITY EDUCATION - 10 - REDUCED INEQUALITIES

adequate school facilities and a comprehensive curriculum		
Theme: Rights related to name, identity & nationality		
Adopt measures to guarantee the right to nationality and prevent cases of statelessness, particularly for minors and people in rural areas	<ul style="list-style-type: none"> - Rights related to name, identity & nationality Groups of Persons: <ul style="list-style-type: none"> - Children - Persons living in rural areas - Stateless persons 	<ul style="list-style-type: none"> - 16 - PEACE, JUSTICE AND STRONG INSTITUTIONS
Theme: Equality & non-discrimination		
Include discrimination and intersectional violence against women, children and adolescents, people with disabilities, indigenous peoples, the LGBTQI community and people of African descent in national plans and strategies	<ul style="list-style-type: none"> - Equality & non-discrimination - Violence against women - National Human Rights Action Plans (or specific areas) / implementation plans - Sexual & gender-based violence - Discrimination against women - Indigenous peoples Groups of Persons: <ul style="list-style-type: none"> - Children - Indigenous peoples - Lesbian, gay, bisexual and transgender and intersex persons (LGBTI) - Women & girls - Minorities/ racial, ethnic, linguistic, religious or descent-based groups - Persons with disabilities 	<ul style="list-style-type: none"> - 5 - GENDER EQUALITY - 10 - REDUCED INEQUALITIES



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