

# GIVING RISE TO RIGHTS: BARRIERS & ENABLERS TO PARTICIPATION OF PERSONS WITH DISABILITIES IN PNG



HUMANITARIAN  
ADVISORY GROUP



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## About the partners

### **World Vision – Research funding agency**

World Vision is a Christian organisation that works with children, families and communities to overcome poverty and injustice. In close cooperation with the Papua New Guinea Assembly of Disabled People (PNGADP) and its members (organisations of persons with disabilities – OPDs), World Vision Australia is implementing the Real Inclusion in Disability Engagement (RIDE) project. This two-year project, funded by the Australian Government, aims to improve the wellbeing and empowerment of people with disabilities in Papua New Guinea and strengthen OPDs' capacity to champion their rights. World Vision also works closely with the Government of Papua New Guinea to strengthen the government's commitment to disability inclusion.

### **Papua New Guinea Assembly of Disabled Persons – Partner organisation**

PNGADP acts as an umbrella organisation for provincial and local OPDs, representing them at the national level in order to promote and protect the rights of persons with disabilities and advocate for their needs.

PNGADP works toward a vision of Papua New Guinea as 'a nation in which persons with disabilities take their place as full and dignified members of society, free from restrictions, abuse and barriers to inclusion'. PNGADP's mission is 'to empower persons with disability to meaningfully participate and positively contribute towards nation building in Papua New Guinea'.<sup>2</sup>

### **Humanitarian Advisory Group – Research lead agency**

Humanitarian Advisory Group (HAG) is at the forefront of current thinking and research on localisation in the humanitarian landscape, with a particular focus on the Pacific. HAG has widely recognised international expertise in humanitarian research, including in the field of disability inclusion. One of HAG's most recent research projects on the topic of inclusion, in partnership with CBM Australia, was published in July 2022. The paper '[Organisations of Persons with Disabilities: Making a Difference in Vanuatu and Solomon Islands](#)' was co-authored by national OPDs in Vanuatu and Solomon Islands; the Pacific Disability Forum also contributed significantly to the research.

### **Ipul Powaseu – National researcher**

Ipul is a recognised leader of the disability movement in PNG and in the Pacific region. Through her different roles as the director of PNGADP for 9 years from 2009 to 2018 and as a board member and ex co-chair of the Pacific Disability Forum (2012-2013), Ipul successfully advocated for the ratification of Convention on the Rights of People with Disability (CRPD) by the PNG government in 2013, as well as had direct inputs into the drafting of the National Policy for Disability. Under Ipul's leadership, the OPD structure in PNG has taken form with the establishment of 20 provincial OPDs, and more recently the establishment of a network for Women with Disability extending across the 20 provinces of the country. Ipul is also involved in global advocacy on a range of topics including on the impact of climate change for persons with disabilities, and the intersectionality between gender, indigeneity and disability.

Ipul's experience as a researcher includes leading the [road accessibility project in PNG](#), [the voices of children with disabilities](#); development of [a national guidelines of assistive devices](#); to name a few.

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# EXECUTIVE SUMMARY



Seventeen years after the United Nation’s adoption of the Convention of the Rights of People with Disabilities, government and development actors worldwide continue to battle with the challenge of creating inclusive societies in which the rights of persons with disabilities are truly protected. At the heart of the issue is the question of participation and representation of persons with disabilities in decision-making, their voice and leadership being recognised, and finding solutions that directly benefit their lives.

In the Pacific and Papua New Guinea (PNG), organisations of persons with disabilities (OPD) act as self-advocates to promote the rights of all persons with disabilities and get their voices heard and to count in decision-making.

**This study is intended to support OPDs and their partners in PNG to better understand and contextualise barriers to inclusion at various levels of PNG society, as well as identify current opportunities and priority actions to overcome these barriers.**

The findings were based on interviews with staff of OPDs, government officials, development partners, and services providers; focus groups with persons with disabilities; document review; and a validation workshop.

The study identified three key barriers to the participation of persons with disabilities and their representatives in decision-making and implementation. These barriers (summarised in the table below) are interlinked, but present differently for different individuals or groups, shaped by a range of factors. The study also identified three priority enablers that can be used to overcome barriers to participation.

	 Barriers	 Enablers
Attitudinal	Continued stigmatisation and marginalisation of persons with disabilities in PNG society	Decision-makers and communities are equipped with the knowledge and skills to enact the rights of persons with disabilities
Institutional	Lack of representation of OPD members in decision-making processes	Strong advocacy capacity of OPDs
Information and communication	Limited understanding of impact and progress to advancing inclusion	Effective two-way information-sharing processes between persons with disabilities and OPDs and other decision-makers

Based on these barriers and enablers, the report identifies 10 opportunities and provides recommendations for OPDs, government at national and sub-national levels, and other organisations, particularly development actors and service providers. These are summarised below and provided in full in section IV of the report.

## SUMMARY OF OPPORTUNITIES AND RECOMMENDATIONS



**Continue and scale up awareness-raising activities** targeted at different actors, focusing on communities, district and provincial authorities, including concrete actions for allies to take

- *OPDs should identify actions based on previous successes. Governments and other agencies should enable this process by documenting past/ongoing activities and scaling up their support.*



**Develop a simple list of main disability support services available** and reliable contacts of sources of information at the national and sub-national levels that can be shared with partners and communities

- *OPDs should lead on giving visibility to their networks and resources, with other agencies supporting this process and dissemination, and government sharing the results at all levels.*



**Develop a national campaign on disability inclusion priorities**

- *Governments and other agencies should support, fund and coordinate a campaign that places OPDs at the forefront.*



**Increase access to core funding and long-term partnerships** to support institutionalisation of OPDs

- *Government and non-government partners must commit to long-term arrangements that include support for OPDs' running costs. OPDs must guide partnership priorities and explain their needs.*



**Support the leadership and voice of OPDs** by increasing their representation at provincial level and supporting the professional development of OPD leaders

- *OPDs should identify and share best practice examples, allowing governments at different levels to build on past successes. Agencies should support OPDs with training and mentoring.*



Support the Papua New Guinea Assembly of Disabled People (PNGADP) and its members to **drive the development of an advocacy plan** to define priority actions to advance rights of persons with disabilities

- *PNGADP should consult and develop an advocacy plan, development agencies and service providers should support the process and implementation, and government should engage and enable it.*



**Support the registration of OPDs as legal entities** to increase their recognition and their financial capacity

- *All actors should work together to increase the number of OPDs registered as legal entities.*



**Increase transparency on the implementation of the National Policy on Disability**

- *The government should lead a public review of the national policy and share information about budgets and plans. OPDs and other agencies should push for this review and engage in its processes.*



**Support OPDs' communication and accountability systems**

- *With technical input and resourcing support from other agencies, OPDs should develop and implement plans for two-way communications with their members.*



**Strengthen provincial government systems** for accountability to and communication with persons with disabilities, including through disability desks and/or divisions for community development.

- *OPDs and governments should work together to identify, document and expand the most effective systems for communication and accountability. Other agencies should support OPDs in this role.*

# INTRODUCTION

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Participation of persons with disabilities in decision-making is not just a matter of upholding their right to participate as equal members of society<sup>3</sup>, but part of building societies in which everyone can flourish. We already know that greater representation of marginalised groups in decision-making can support both of these objectives. For example, an evaluation of the Disaster READY program in the Pacific found that participation of persons with disabilities in decision-making directly contributed to greater inclusion in disaster preparedness and response efforts<sup>4</sup>. Other research has provided evidence of the benefits of diversity in leadership<sup>5</sup>; however, several barriers continue to prevent Pacific Islanders with disabilities from participating, as well as their voices from being heard, often resulting in inadequate efforts to promote inclusion and visible gaps in access to basic services (such as education, health and justice<sup>6</sup>), discrimination in employment, and human rights violations.

Papua New Guinea (PNG) faces all the issues mentioned above. Although data on the situation of persons with disabilities in PNG is scarce, it is clear that many barriers to inclusion persist<sup>7</sup>, including some that prevent organisations of persons with disability (OPDs) from effectively representing the voice of and advocating for the rights of persons with disabilities in PNG at national, provincial and community levels.

International frameworks for understanding barriers to inclusion already exist<sup>8</sup>, but these don't necessarily capture the reality and complexity of different contexts, nor point to priority areas for overcoming these barriers in societies structured differently. Consequently, World Vision Australia, in partnership with the Papua New Guinea Assembly of Disabled Persons (PNGADP), commissioned the present study to **explore and contextualise barriers to inclusion, and identify key enablers and opportunities to promote greater participation in decision-making of persons with disabilities in PNG**. The study was based on the assumption that greater participation of persons with disabilities in decision-making is essential to advancing their rights and inclusion in society more broadly and across multiple sectors.

## Disability

The United Nations' Convention on the Rights of People with Disabilities (CRPD) describes 'disability' as resulting from **'the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'**. This concept is also integrated in PNG's National Policy on Disability.<sup>9</sup>

## Organisations of persons with disabilities (OPD)

OPDs are representative organisations that advocate for and promote the rights of persons with disabilities. A key element of OPDs is that most staff (at least 51%) must be persons with disabilities themselves. OPDs are distinct from service providers, although many of them also provide services, such as assistive devices or other health and educational services for persons with disabilities. Whilst OPDs may advocate for the rights of persons with disabilities, they are not self-advocates.

## REPORT OUTLINE

**The first section** of the report describes the scope, approach and methodology of the study.

**The second section**, called 'Disability in PNG', provides an overview of the situation of persons with disabilities in PNG, their existing representation structure, and identifies relevant socio-economic factors of exclusion. It outlines the diversity of experiences of persons with disabilities, and provides greater understanding of overlapping factors that can amplify the barriers to inclusion presented in section III.

**The third section** of the report, 'Barriers and enablers', articulates three barriers and three enablers of inclusion in PNG along with opportunities to overcome these barriers. Key opportunities presented were identified and refined in close consultation with a local researcher and OPD representatives.

**The fourth and final section** of the report presents recommendations designed to help specific actors – OPDs, government actors, and other development actors and service providers – to improve inclusion of persons with disabilities in PNG.



# I. ABOUT THIS RESEARCH

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## Box B. Inclusive research

The present study was guided by '[Research for All](#)', and included the following strategies to ensure inclusiveness throughout the research and dissemination process.

**Consent and power dynamics:** all study participants were fully informed of the purpose and intended use of the research. A Plain Language Statement was offered and informed consent obtained before each interview. Participants were reminded of their right to skip any questions and withdraw from interviews at any point. An experienced Papua New Guinean researcher with lived experience of disability conducted all in-country research, thereby minimising potential power differences between the researchers and research participants due to cultural, gender, social and language dynamics.

**Reasonable accommodations:** support for the participation of persons with disabilities in this research was ensured via: 1) a dedicated budget line as part of the research project representing 3% of the total project value, used to meet various needs of persons with disabilities that arose during the research; 2) World Vision's ongoing partnership with OPDs and PNGADP, which facilitated compensation for their time and contributions to the research.

**Support to persons with disabilities:** participation of persons with disabilities throughout the research process was ensured by the employment of a consultant with relevant professional and lived experience to lead data collection and contribute to research design, analysis and dissemination. PNGADP members were also consulted at key stages of the research, including the design, analysis, and final report drafting phases. Contributions from both PNGADP and the in-country researcher are acknowledged in the report, which also supports their visibility.

**Accessible products:** The report follows Level A of the [WEB content accessibility guidelines version 2.0 \(WCAG 2.0\)](#) for written products. Any dissemination event following the publication of the report will be made accessible to OPD members.

## RESEARCH QUESTIONS

The study sought to answer the following three research questions:

1. What are the **barriers to and enablers** of OPDs and persons with disabilities contributing to decision-making in PNG?
2. Which **socio-economic factors** in PNG heighten barriers to participation in decision-making for persons with disabilities?
3. What **opportunities** exist in PNG to lower the main barriers to persons with disabilities' inclusion in decision-making?

## METHODOLOGY

This study was a **qualitative enquiry** into the issue of disability inclusion in contemporary PNG. Whilst the concept of inclusion of persons with disabilities and their rights is a vast topic, the researchers chose to explore the barriers to and enablers of inclusion in relation to the **participation of persons with disabilities in decision-making** specifically. Findings were developed from examples of successful and less successful engagement of persons with disabilities in urban, semi-urban and rural contexts of PNG society, corresponding to the country's three levels of governance – national, provincial and district/village levels.

## DATA SOURCES

The study collected data via a desk review exercise and primary data collection. Figure 1 below summarises the methods used. For further information on the makeup of research participants, see Annex I.

Figure 1: Methods



## LIMITATIONS

The study had three limitations, described below.

- **Scope:** by exploring barriers using a qualitative approach, the analysis presented in this report does not fill the current gap in statistics on persons with disabilities in PNG or document the barriers to access to basic services and fulfilment of their diverse human rights. It does not provide a review of the policies in place, but rather an investigation of the barriers and opportunities for OPDs and persons with disabilities to be

systematically involved in decision-making about policy and monitoring of policy implementation at various levels of society.

- **Representativity:** the geographic and demographic diversity of PNG (600 islands with 1,000 distinct ethnic groups speaking over 800 languages), as well as the diversity of experiences of persons with disabilities, means the study could not be representative of the entire country.
- **Sample design:** The study did not include children with disabilities, and all participants were at least 18 years old. Thirty-seven persons with disabilities were consulted, including persons with one or more physical, sensory, intellectual and/or psychosocial disability<sup>10</sup>.

## II. DISABILITY IN PNG

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### COUNTRY CONTEXT



Spread across 600 islands, with over 800 spoken languages, Papua New Guinea is one of the most culturally diverse countries<sup>11</sup>. The diversity of the country is also visible in its socio-economic make up, ranging from traditional village-based life, dependent on subsistence and small cash-crop agriculture, to urban life in the capital and provincial cities<sup>12</sup>. More than half of the population is under the age of 23<sup>13</sup>.

It is estimated that that approximately **15% of the population in PNG have a disability**<sup>14</sup>. However, the only available official data was collected in 2009–10<sup>15</sup> and was mostly focused on mobility difficulties, finding that 9.8% of the population experience some difficulty in using steps. This survey excluded intellectual, visual and hearing impairments.

### KEY POLICY FRAMEWORKS

The PNG government ratified the **CRPD** in 2013. It committed to report on progress to the CPRD Committee after two years and every four years after that, but no formal reporting has occurred to date.<sup>16</sup> It also promulgated the **National Policy on Disability 2015-2025**, and the **National Public Service Policy on Gender Equity and Social Inclusion (GESI)** in 2013<sup>17</sup>.

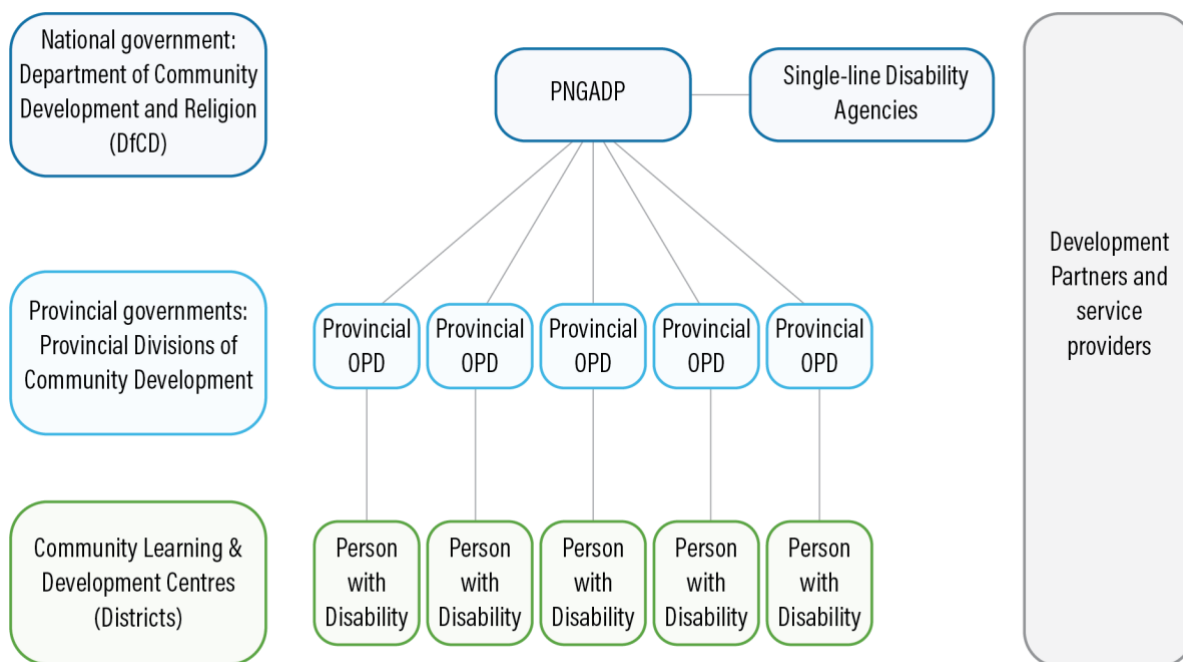
The National Policy on Disability is the main national strategic plan for advancing and protecting the rights of persons with disabilities in PNG. The policy outlines priorities and strategies to promote rights and advocacy, improve services, and improve institutional, legal and financial frameworks for the disability sector. The policy also describes key resources necessary to its implementation, including implementation and coordination arrangements, a monitoring and evaluation system, and a budget framework. The National Public Service (NPS) Policy on GESI aims to promote GESI across PNG's NPS. Notably, it raises the issue of the low representation of persons with disabilities within the public sector and underlying issues of awareness, access and discrimination in employment that contribute to it. **However, the extent to which both policies are being implemented is unclear** (see section III on barriers for further information).

### REPRESENTATION OF PERSONS WITH DISABILITIES

In PNG, several OPDs officially represent persons with disabilities following a decentralised structure mirroring that of government (Figure 2). PNGADP works as an umbrella body, coordinating all OPDs in the country. Its board members consist of representatives of OPDs from all provinces in PNG. Currently, PNGADP has 27

members, including 22 OPDs representing the 22 provinces, and five members from specialised OPDs representing the voices of specific groups such as women, youth, blind, deaf and paraquad (people with paraplegia or quadriplegia).<sup>18</sup> By aligning with the government structure, the intention is that persons with disabilities are represented and engage with authorities at national, provincial and district levels.

**Figure 2: OPD structure (Updated from 2012 PNGADP’s Internal Document)**



## FACTORS OF EXCLUSION IN PNG

Persons with disabilities’ experiences of exclusion are diverse due to their varied socio-economic factors and impairments. Reflecting on ‘whose voice is least represented in current OPD structures in PNG’ in interviews helped to identify examples (matching many of those revealed in the desk review) of people most at risk of exclusion in the PNG context.

### Gender & age

*‘Women with disabilities do not generally attend [OPD meetings] and my opinion that is due to the patriarchal attitudes against women and more so stigma associated with disability often relegating women with disabilities to be further marginalised.’ OPD Staff*

*‘Women with disabilities are often not represented because of how we are perceived as the inferior gender. Often men with disabilities take lead and, we, women with disabilities, do not participate equally. [...] we need to have our own women OPD network [in the province] so we can advocate on our specific issues, so we can have our own voice.’ Woman with Disability*

Both women and youth are given specific attention in the National Policy on Disability under priorities 1.5 and 1.6 on ‘strengthening advocacy and right of persons with disabilities’. This, and a network of women with disabilities and a recently created youth with disability OPD at the national level, could give the impression that both groups are well established and positioned to get their voices heard. However, this impression vanishes at the provincial and community level, where patriarchal and hierarchical culture prevails and continues to undermine their voices and contribution to leadership<sup>19</sup>.

## Specific disabilities

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*‘We do not see many persons with hearing impairments because we do not have sign language interpreters, and secondly many of our rural persons with hearing impairment do not understand the formal sign language.’ OPD Staff*

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*‘People with mental health issues do not participate because we are afraid they might become violent.’ Person with Disability*

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*‘People with intellectual and psychosocial disabilities are not participating because they are often not encourage[ed] by their families to attend.’ OPD Staff*

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In this study, people with specific disabilities were identified as less likely to participate in the OPD network and in community life in general. These included deaf people, vision-impaired people, and people living with an intellectual or psychosocial disability. Reasons for this varied from the lack of specialised services to facilitate communication, such as sign language interpreters and signing schools, to the lack of learning facilities for vision-impaired people to develop mobility skills, and the lack of screening for and lack of understanding of how to communicate with people with intellectual and psychosocial disabilities.

## Remote and conflict areas

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*‘Many of our persons with disabilities in the rural level are not involved much in OPDs’ activities because of the costs of transportation and lack of financial support.’ OPD Staff*

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Tribal fights over land or other grievances continue to affect mobility and safety in several provinces of the country. The difficult topography and cost of travel in PNG also prevents access to services; many OPD staff reported difficulties in reaching out to their members in remote and unsafe places.

## Education

There is no data on access to education by persons with disabilities in PNG. However, international evidence suggests that their access to education is lower than for people without disabilities, so are more likely to be illiterate, reducing their ability to access information and participate in society<sup>20</sup>.



## Income and subsistence

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*'The issues of burden of care is so evident in the community and this affects the whole family as well. You heard the story of the young man who had to provide care for his father and uncle and this affects their family as well. When he is looking after his father and his uncle, who will go out and grow food for them? This is a real challenge for me as a councillor for this village.'* **Community Leader**

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It is evident that in order to participate in society, persons with disabilities in PNG often rely on family members to accompany them. For the poorest families, this might be impossible, given the economic cost of missing a day of work and its impact on the household.

## HIV

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*'People working in the NPS do not have a high level of awareness of HIV/AIDS causes, cures or prevention, and discrimination exists against individuals who are HIV positive.'* **NPS GESI Policy**

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An estimated 45,000 people are living with HIV in PNG – by far the highest prevalence in the region<sup>21</sup>. Stigma against HIV-positive people is strong and interlinked with stigma against most at-risk populations, namely women and girls who sell and exchange sex, men who have sex with men, and transgender women<sup>22</sup>. According to a 2018 survey, these groups were also found to be at high risk of discrimination and violence, including from the police and their communities.<sup>23</sup> According to a recent Joint United Nations Programme on HIV/AIDS (UNAIDS) survey, up to 64% of Papua New Guineans would not 'buy fresh vegetables from a shopkeeper or vendor if they knew that this person had HIV'. In the same survey, up to 74% of Papua New Guineans stated that they did not think that 'children living with HIV should be able to attend school with children who are HIV negative'.<sup>24</sup>

## LGBTQI

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*'Three out of four [men who have sex with men] in the second largest city, Lae, reported having experienced violence related to their sexuality or sexual identity.'* **Kauntim mi Tu (count us) Survey**

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The topic of the rights of the LGBTQI community in PNG is a particularly sensitive one given the ongoing criminalisation of male-to-male sex<sup>25</sup>. The question of their representation within the OPD movement in the region is also being debated currently, and consensus on the question has not been reached to date.

As these examples show, various factors can interact to increase marginalisation. Figure 3 summarises the concerns about exclusion most frequently raised in interviews, recognising that this list does not necessarily cover all marginalised or underrepresented groups in PNG.

Figure 3: Examples of people most at risk of exclusion in PNG

**Women and girls** HIV-positive people  
People from low-income households

**People living in remote and conflict-affected areas**  
People with intellectual and psychosocial types of disabilities

LGBTQI community **Youth** Illiterate/low education  
People requiring specific services to participate (deaf and blind)

### III. BARRIERS AND ENABLERS

#### KEY BARRIERS FACED BY PERSONS WITH DISABILITIES

Barriers to participation in decision-making are multiple, complex, and as illustrated in the previous section, experienced differently by different people. The **present study identified three main barriers or priority issues impeding the participation of persons with disabilities** in PNG today. Identifying priority barriers to overcome is important in advancing change, even though this means some barriers will be deprioritised, at least in the short term. For each barrier (summarised in Figure 4), the report identifies one high-level **enabler**, as well as specific recommendations (outlined in section IV).

Summary of key barriers to the participation of persons with disabilities in PNG

	Barrier 1: Attitudinal	Barrier 2: Institutional	Barrier 3: Information and communication
What is the barrier?	Continued stigmatisation and marginalisation of persons with disabilities in PNG society	Lack of representation of OPD members in decision-making processes	Limited understanding of progress towards advancing inclusion
Why is this a priority?	It prevents progress in overcoming barriers of other kinds	It limits OPDs’ institutional development and voice	It reduces incentive and commitment to work towards change
Where is it visible?	All stakeholders raised this as a widespread and systemic barrier	Low representation of OPD members in provincial and local government structures and weak partnerships between OPDs and other agencies	Cascading challenges, starting at the national government level, and communication problems between OPDs and their members
How does it relate to other key barriers?	Negative perceptions of persons with disabilities mean they are not offered opportunities to participate in decision-making, reinforcing existing institutional biases and lack of understanding	OPDs’ resources are stretched too thin, making it harder to do all the work well or document successes. This means that motivation to engage drops and stigma goes unchallenged	Lack of transparency reduces accountability between government and stakeholders and between OPDs and members, weakening institutional relationships and encouraging marginalisation

## **BARRIER 1 – ATTITUDINAL: Continued stigmatisation and marginalisation of persons with disabilities**

Negative and undermining attitudes against persons with disabilities continues to hinder their participation in community life. **Other environmental barriers – such as lack of transport, inaccessibility of venues, and lack of assistive devices and support – were also raised as important but found to be secondary** to the underlying issue of not being welcome at the table in the first place.

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*‘The main issue is the perceptions about our disabilities that we are not able to undertake any activities or contribute to activities. Our carers and parents will often speak on our behalf.’ Person with Disability*

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*‘When I entered the government building, people could not believe that I was there for an interview and they asked me to leave. They were very apologetic afterwards.’ Researcher*

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All stakeholders recognised the negative impact of common attitudes and underlying perceptions of persons with disabilities, who are **generally perceived as people in need of assistance rather than as people with the rights and abilities to participate in decision-making** about their own lives and as part of the community<sup>26</sup>.

Such perceptions, whether rooted in cultural beliefs<sup>27</sup>, common stereotypes<sup>28</sup>, and/or a lack of understanding of disability<sup>29</sup>, directly **affect persons with disabilities’ self-esteem and confidence to participate**. This was particularly true for women with disabilities interviewed in rural areas and who themselves reported ‘feeling useless’.

Such beliefs of uselessness, sometimes held by persons with disabilities themselves, also raise the question of **whether persons with disabilities are given the means to participate in the first place**. Access to information, as well as access to basic services such as health and education, can determine one’s ability and confidence to participate. Whilst there is little data on access to basic services by persons with disabilities in PNG, their marginalisation is likely to reinforce stigma and negative perceptions. In short, when opportunities for people to participate are few, so are opportunities for them to show that their participation is possible as well as beneficial.

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*‘We need to do more sensitisation training on the rights of persons with disabilities so that people do not see us as useless or needing sympathy [...] this needs to happen in rural communities where the bulk of people with disabilities live.’ OPD Staff*

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## **BARRIER 2 – INSTITUTIONAL: Lack of representation of OPD members in decision-making processes**

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*‘The representation of people working in the NPS is not reflective of the demographic of the community, having regard to women, people living with disabilities and those from diverse or disadvantaged backgrounds.’ NPS GESI Policy*

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Despite the existence of policies promoting and protecting the representation of persons with disabilities at different levels of governance and across several departments, the actual **representation of persons with disabilities at provincial and district levels is low**. When this study was underway, only two provinces of 22

included an OPD member as part of their Provincial Executive Council<sup>30</sup>. OPDs also report **mostly weak and ad hoc partnerships with development partners and service providers**<sup>31</sup>.

The main reasons advanced for inconsistent inclusion of persons with disabilities in decision-making were:

- lack of awareness of policies and disability (affected by barrier 1 above)
- lack of transparency and accountability in policy implementation (see barrier 3 below)
- lack of resources and trust in the institutional capacity of OPDs<sup>32</sup>.

The large number of forums relevant to the experiences of persons with disabilities and lack of coordination between different stakeholders exacerbate these issues, meaning that OPDs' very limited resources are stretched even thinner.

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*'Most of the actors within the disability space are working in isolation. A coordinated mechanism needs to be in place to guide the implementation of the policy [...] For example, the Inclusive Education unit works under the National Department of Education, the Community Base Rehabilitation comes under the Department for Community Development, but the system coordinating disability mainstreaming at the national and sub-national level only exist in print.'* Service Provider

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Resourcing and trust are closely related. The basic operations of OPDs in PNG remain largely dependent on external resources, often tied to supporting other actors' agendas and project cycles<sup>33</sup>. This decreases OPDs' ability to allocate time and other resources to their own priorities, development and operations. Most provincial and community-level OPD staff are volunteers and reported lacking resources to meet and engage with their members in communities as well as with their colleagues from other OPDs. Significant factors in this are the high cost of travel and communication in PNG, as well as the geographic and technical challenges of coordinating a national movement without minimum operational costs being covered. As a result, operational and strategic gaps emerge. For example, PNGADP's annual board meeting have tend to occur on an adhoc basis rather than annual basis. In turn, these gaps undermine the confidence of external stakeholders and can affect the likelihood of OPDs receiving funding, especially unearmarked funding. **In a context of scarce resources and insufficient institutional support, the institutional capacity of OPDs to coordinate and advocate on behalf of their members is precarious.**

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*'Without core funding support from the government we are not able to meet the demands of our OPD affiliates, leading to some reluctance to provide reports to the Secretariat.'* PNGADP

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*'The need for continuous funding is a major challenge for us. Costs of transportation [are] high and most of us work on a volunteer basis. [...] Reaching the bulk of persons with disabilities living in the rural areas is a real challenge.'* OPD Staff

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### **BARRIER 3 – INFORMATION & COMMUNICATION: Limited understandings of impact and progress toward inclusion**

A general lack of information, communication and transparency on progress toward inclusion priorities set by national policies and OPDs themselves, limits OPD staff's and persons with disabilities' understanding of how to participate, and erodes their motivation to participate.

The establishment of the National Policy on Disability is regarded as an important milestone in supporting the disability inclusion movement in PNG. However, **no formal coordinated monitoring process** supports the policy's implementation, despite the monitoring section of the policy planning for independent bi-annual reviews (as the CPRD recommends), a mid-term review involving all stakeholders, and social accountability and community engagement opportunities such as community forums to collect feedback on plans and media communication on progress and issues.

The policy also provides for annual budget planning which, when it has occurred, **has lacked transparency on resources available** for OPDs and provincial governments to progress the policy. This is not surprising given **the key implementing and coordinating bodies planned for the strategy have not been set up** to the exception of the National Advisory Committee on Disability (NACD). Other planned bodies including Provincial Coordinating Committees on Disability, and a specialist Disability Reference Group (to be set up by PNGADP) comprising experienced individuals from all types of disability, are non-existent. Blockages at national level are therefore affecting other levels of government. This lack of visibility on progress toward implementing the strategy has left many actors wondering what can or should be done next.

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*'Stakeholders cited accountability and performance breaches as major challenges of the past. Reporting lines were unclear in some instances and grant acquittals were not furnished in other cases. Planning forums were held on an opportunistic basis rather than as a structured system and the NACD itself, hampered by a number of issues, were unable to meet regularly. The NPD responds by establishing a performance management framework, made up of:*

*An Annual Planning and Budgeting system: in line with the established system but updated to include a plan and budget consolidation process*

*A monitoring and evaluation framework: linking in stakeholders to participate in assessing NPD outcomes and creating social accountability opportunities*

*Structured NPD reviews and CRPD reporting system.'* *National Policy on Disability, p. 43*

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**At the OPD level**, the lack of evidence about and links between OPDs' day-to-day activities and strategic objectives also erodes persons with disabilities' motivation to participate, including OPD staff themselves, most of whom are volunteers. Most of OPDs' activities at the provincial level focus on awareness raising (when funding is available) and the collection of personal data on persons with disabilities, mostly from service providers<sup>34</sup>. However, **none of the OPD staff interviewed could articulate how this data has been used for advocacy or other purposes**. While OPDs face challenges in coordinating, collecting, storing and analysing data for advocacy purposes<sup>35</sup>, the lack of understanding of outcomes from their work and lack of communication back to communities raises frustrations within the network. OPD staff themselves and a few community members with disabilities **questioned the benefits of being part of the network**<sup>36</sup>. One OPD member also



expressed reluctance to visit communities where expectations have been raised but there are no resources to support people’s participation and meet needs.

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*‘To be honest we have not made any positive impact. Although we have tried to create awareness, no one seem to recognise our rights.’ OPD Staff*

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## ENABLERS OF PARTICIPATION OF PERSONS WITH DISABILITIES IN PNG

	<b>Enabler 1: Attitudinal</b>	<b>Enabler 2: Institutional</b>	<b>Enabler 3: Information and communication</b>
<b>What is the enabler?</b>	Decision-makers and communities are equipped with the knowledge and skills to enact the rights of persons with disabilities	Strong advocacy capacity of OPDs	Effective two-way information sharing processes between persons with disabilities and OPDs and other decision-makers
<b>Why is this a priority?</b>	Changes in attitude and understanding can lead to more inclusive decision-making and policies	Leadership by self-advocates creates the conditions for others to become allies	Persons with disabilities are calling for greater access to information and participation
<b>Where is it visible?</b>	Awareness-raising efforts by OPDs at national and provincial level provide good practice examples to build on	Existing partnerships are a foundation for more holistic support to OPDs as institutions, and can support the growth of individual leaders with lived experience of disability	Some provinces have dedicated mechanisms for engaging with OPDs and their members, which can be transferred or scaled up
<b>How does it relate to other key enablers?</b>	With more people who understand how to support the participation of persons with disabilities, there will be more momentum to challenge institutional barriers and leverage improved communication	Recognising some of the power imbalances between OPDs and other actors can create space for stronger dialogues to inform decision-making and accountability	Channels for meaningful participation are necessary to understand the diverse and evolving priorities of persons with disabilities and whether actions are working



## **ENABLER 1 ATTITUDINAL: Decision-makers and communities are equipped with knowledge and skills to enact the rights of persons with disabilities**

This enabler is rooted in the personal and collective experience of people (including the research team itself) **undergoing disability training and becoming an ally to the disability movement as a result**. Several OPD staff, government partners and other development partners consulted as part of the study gave examples of **positive outcomes from awareness-raising activities** led by OPDs in PNG. This is particularly true at the national and provincial levels, on which most awareness-raising efforts have focused. For example, the inclusion of an OPD representative in the Lae City Council to advise on the development of the city market was cited as being possible only thanks to the Council leaders' awareness of disability from their interactions with OPD leaders<sup>37</sup>.

Whilst all stakeholders raised the need to scale up awareness-raising efforts on the rights of persons with disabilities, including to rural communities, OPD staff also warned of **the risk of raising false expectations if these trainings are not accompanied by the necessary resources and identification of concrete actions** to protect and enact these rights<sup>38</sup>.

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*'Joining hands with other stakeholders helps us to be effective in our advocacy work. They become our voice as well.'* OPD Staff

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Awareness raising is not the sole responsibility of OPDs and cannot be achieved by them alone. Several interviewees called for **greater collaboration and coordination of efforts** between OPDs, government, and service providers and other development actors<sup>39</sup>. Greater coordination and stronger partnerships could promote awareness raising within key partner organisations, as well as at community level, by using partners' own networks to channel and share information more broadly. This would be facilitated by the decentralised structure of OPDs (*see section II*)<sup>40</sup>. The idea of a joint multimedia campaign around key dates, such as the National Day of Persons with Disability, was also raised as an idea by one international partner. Another idea was to develop a simple mapping of services, support mechanisms and/or information sources to help multiple actors share information about disability, and promote access to basic services by persons with disabilities, recognising that the fulfilment of basic needs also contributes to people's capacity to participate.



### **Opportunities:**

- Continue and scale up awareness-raising activities targeted at different actors, focusing on communities and district and provincial authorities, including concrete actions for allies to take
- Develop a simple list of main disability support services and reliable contacts of sources of information at the national and sub-national levels that can be shared with partners and communities
- Develop a national campaign on inclusion priorities in PNG (e.g. on the National Day of Persons with Disability)



## ENABLER 2 – INSTITUTIONAL: Strong advocacy capacity of OPDs

Strong leadership and voice of persons with disabilities is crucial to advancing their rights and supporting OPDs in the Pacific to play a unique role as self-advocates for greater inclusion<sup>41</sup>. In this study, OPD staff and persons with disabilities demonstrated eagerness to participate and called for greater empowerment and representation of their community. **The strengthening of the OPD network and its organisational and advocacy capacity is therefore a priority parallel to empowering and supporting individual leadership.**

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*‘We are beginning to see OPDs being recognised and becoming members of the Provincial Executive Council [...] So far two provinces have OPD representatives at this political decision-making level, and by being represented at the highest political governing system in the province, voices and issues of persons with disabilities are further amplified.’* **Government Partner**

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*‘We do not have an advocacy plan but by identifying these priority plans, we would like to have our persons with disabilities at the district level to empower them to have a voice at the district level.’* **OPD Staff**

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**At the institutional level**, stronger advocacy capacity and recognition of OPDs as partners of choice is needed to advance their inclusion and engagement with decision-makers. This could include initiatives such as the **updating of PNGADP’s Advocacy Strategic Plan**, which ended in 2020<sup>42</sup>, and which has the potential to strengthen the OPD network and voice, as well as serve as a basis to engage and rally key partners and stakeholders behind OPDs’ own leadership. (See also additional recommendations on the development of PNGADP’s Advocacy Plan in a separate document.) Another idea raised by OPD staff was to support the **legal registration of regional OPDs**; most remain unregistered to date, and as a result are unable to directly manage funds. It is also the responsibility of both development partners and government actors to commit to **longer-term and respectful partnerships** to support the representation of persons with disabilities, as well as the responsibility of OPDs to demonstrate initiative and lead on the definition of priorities to advance inclusion in PNG<sup>43</sup>.

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*‘The leadership training for our leaders has given them a much broader perspective and an understanding of their rights and they are becoming more aware of how to advocate effectively with the provincial government and other partners and NGOs and in the community for the recognition of their rights. Thanks to this training, one OPD leader was able to step up as a representative on the Lae City Council for the redevelopment of the Lae Market.’* **OPD Staff**

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**At the individual level**, the present study collected some evidence of positive outcomes from capacity-building efforts such as **leadership training and mentoring support** to ODP representatives by various development partners. The mentoring of OPD leaders is becoming more and more critical as their roles as advisor and representatives of the disability community expand.



### Opportunities:

- Increase access to core funding and long-term partnerships to support stronger institutionalisation of OPDs
- Support the leadership and voice of OPDs by increasing their representation at provincial level and supporting the professional development of leaders
- Support PNGADP to drive the development of an advocacy strategy and plan in coordination with its members
- Support the registration of OPDs as legal entities to increase their recognition by government partners and their financial capacity.



### ENABLER 3 – INFORMATION & COMMUNICATION: Effective two-way information sharing processes between persons with disabilities and OPDs and other decision-makers

Access to information and accountability is not just a right of persons with disabilities, it is also essential to the credibility of key institutions, including the government and OPDs.

**At the national level**, the fact that the National Policy on Disability exist is in itself a great opportunity for targeted advocacy from OPDs, who are right to demand greater visibility on progress and implementation of the policy. **At the sub-national level**, the lack of a Provincial Coordinating Committee (as per the National Policy) has not prevented some provincial authorities from working to improve inclusion, usually through the Provincial Community Development Division. In a few provinces, the authorities have developed **Disability Desks** with the purpose of facilitating sharing and access to information, as well as progressing inclusion mainstreaming at the provincial and community levels. While the capacity of these divisions and desks varies between provinces, OPDs should partner and engage further with these structures and service providers to ensure effective and meaningful sharing of information and communication with communities.

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*‘Without a systematic framework in place, rights and priorities are considered on an ad hoc basis. When OPD have needs they would approach us and we would work out their priorities. At the moment we do not have any framework to systematically involve OPDs in decision-making. And for that reason, the Provincial Government has endorsed the set-up of the Disability Desk within the Community Development Division. This Desk will develop policies and strategies to make sure persons with disabilities are represented in various decision-making boards within the province (education, health, physical infrastructure) and will also roll out to the districts and the ward levels.’ Provincial Government Partner*

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Overall, persons with disabilities are calling for greater access to information and participation, and it is the responsibility of government entities and OPDs to develop strong accountability channels. **In the case of OPDs**, this could be facilitated by a simple **communication Plan** which could serve their advocacy plan, and be resourced as part of OPDs’ minimum operational costs as a key pillar to their organisation. **Support from development partners** will be needed, and should be facilitated by having such plan in place to rally support and

guide partnerships' priorities. (See also *additional recommendations on the development of PNGADP's communication in a separate document*).





### **Opportunities:**


- Increase transparency in the implementation of the National Policy on Disability by conducting a public review and communicating on government implementation budget available
- Support OPDs' communication and accountability systems
- Strengthen provincial government systems' accountability to and communication with persons with disabilities, including through disability desks and/or divisions for community development

Enablers are longer term objectives; their achievement will bring about change and lower identified barriers to participation for persons with disabilities. The next section recommends actions to be taken by OPDs, governments, and development actors, both separately and in collaboration, to achieve these goals.




## IV. RECOMMENDATIONS




The opportunities and recommendations below are prioritised and limited to three or four per enabler and per actor in order to facilitate uptake. The recommendations recognise the centrality of OPDs' leadership and advocacy roles, while acknowledging the importance of other allies, notably in providing technical support, amplifying messages, contributing resources and adopting inclusive approaches in their own ways of working. Each recommendation



indicates whether it represents a new action  or takes advantage of existing opportunities to scale up .

Enabler	Opportunity	Recommended role: OPDs	Recommended role: PNG government	Recommended role: development actors & service providers
1	 <p><b>Continue and scale up awareness-raising activities targeted at various actors, especially communities, district and provincial authorities, including concrete actions for allies to take.</b></p>	<p>Analyse past/ongoing awareness-raising activities to identify future actions and seek support to scale up activities.</p>	<p>Support OPD learning and documenting of past/ongoing awareness-raising activities, including the identification of concrete actions.</p>	<p>Support OPD learning and documenting of past/ongoing awareness-raising activities and scale up support for activities, including the identification of concrete actions.</p>



Enabler	Opportunity	Recommended role: OPDs	Recommended role: PNG government	Recommended role: development actors & service providers
	 <p><b>Develop a simple list of main disability support services and reliable contacts of sources of information at the national and sub-national levels that can be shared with partners and communities.</b></p>	<p>Prepare and disseminate list, liaise with governments.</p>	<p>Ensure all provincial and district authorities are aware of and actively disseminating the list.</p>	<p>Support OPDs as they lead the process, e.g. by sharing information, supporting production, and disseminating.</p>
	 <p><b>Develop a national campaign on inclusion priorities in PNG (e.g. on the National Day of Persons with Disability).</b></p>	<p>Lead coordination and implementation of the campaign.</p>	<p>Support, fund, and coordinate campaign.</p>	<p>Support, fund and coordinate campaign.</p>
2	 <p><b>Increase access to core funding and long-term partnerships to support stronger institutionalisation of OPDs.</b></p>	<p>Request partners to commit to the long term, and align with OPDs' own strategies and priorities.</p>	<p>Commit and resource long-term partnerships with OPDs, including ongoing support to their running costs and compensating them for their engagement and participation as much as possible.</p>	<p>Commit and resource long-term partnerships with OPDs, including their running costs, and compensate OPDs for their engagement and participation in meetings.</p>

Enabler	Opportunity	Recommended role: OPDs	Recommended role: PNG government	Recommended role: development actors & service providers
	 <p><b>Support the leadership and voice of OPDs by increasing their representation at provincial level and supporting the professional development of leaders.</b></p>	<p>Advocate for stronger representation of OPDs in provincial decision-making bodies by sharing best practice examples from the two provinces that include representation of OPDs within their Provincial Executive Councils.</p>	<p>Learn from the two provinces that include representation of OPDs within their Provincial Executive Councils, and consider ways to develop similar representation within other provinces.</p>	<p>Continue to support OPDs' organisational capacity and leadership via training and mentoring programs.</p>
	 <p><b>Support PNGADP to drive the development of an advocacy plan in coordination with its members.</b></p>	<p>Develop an Advocacy Plan in consultation with members and other stakeholders, and engage existing and potential partners to resource it.</p> <p><i>(See also recommendations to PNGADP on the development of advocacy tools).</i></p>	<p>Invite PNGADP to provide annual cross-departmental briefings on their advocacy plan, as part of listening and responding to OPDs' advocacy priorities to progress inclusion.</p>	<p>Support and fund the development of PNGADP's advocacy plan, and commit to support and fund activities of common interest.</p>
	 <p><b>Support the registration of OPDs as legal entities to increase their recognition by government partners and their financial capacity.</b></p>	<p>Seek registration and share learning with other OPDs.</p>	<p>Run a registration drive for OPDs.</p>	<p>Offer institutional and administrative support to OPDs seeking registration.</p>

Enabler	Opportunity	Recommended role: OPDs	Recommended role: PNG government	Recommended role: development actors & service providers
3	 <p><b>Increase transparency on the implementation of the National Policy on Disability by conducting a public review and communicating on budget availability to implement the policy.</b></p>	<p>In coordination development partners and allies, advocate for a review of and greater transparency in the implementation of the National Policy on Disability.</p>	<p>Revisit priorities of the National Policy for Disability via a multi-stakeholders review and communicate on budget availability to implement the policy at various levels.</p>	<p>In coordination with OPDs, advocate for a review of and greater transparency in the implementation of the National Policy on Disability.</p>
	 <p><b>Support OPDs' communication and accountability systems.</b></p>	<p>Implement communicating plan and including seek for resourcing. <i>(See also recommendations to PNGADP on the development of communication tools).</i></p>	<p>Coordinate with OPDs to identify existing communication channels and accountability mechanisms as part of the government structure which could be used or strengthen to reach out to communities and OPD members in particular.</p>	<p>Coordinate with OPDs to identify and optimise existing communication channels and accountability mechanisms as part of development actors' and service providers' structures, and identify any gaps.</p>

Enabler	Opportunity	Recommended role: OPDs	Recommended role: PNG government	Recommended role: development actors & service providers
	 <p><b>Strengthen provincial government systems for accountability to and communication with persons with disabilities, including through disability desks and/or divisions for community development.</b></p>	<p>Strengthen partnerships with the provincial division for community development and/or disability desks (if existing) as part of OPDs’ advocacy and communication strategies.</p>	<p>Document and promote the development of disability desks, if they prove to be effective in mainstreaming inclusion and amplifying the voice of persons with disabilities and OPDs at the sub-national level.</p>	<p>Support OPDs’ engagement with government counterparts where possible.</p>

# ANNEX I: LIST OF STAKEHOLDERS

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Total number of participants: 43

Total number of participants with a disability: 35

Type of impairments included:

- Physical (21 persons)
- Sensory (10 persons)
- Intellectual and/or psychosocial disability (3 persons)
- Multiple disabilities (1 person)

Stakeholder	Gender	
	F	M
PNGADP	-	1
Regional OPDs	4	2
Community members	18	12
National/local government	-	3
Development partners	2	-
Service providers	-	1

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## ANNEX III: ABBREVIATIONS

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CRPD	Convention on the Rights of Persons with Disabilities
DFAT	Department of Foreign Affairs and Trade [Australia]
GESI	Gender Equity and Social Inclusion
HAG	Humanitarian Advisory Group
LGBTQI	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Intersex
NGO	Non-Governmental Organisation
NPD	National Policy on Disability
NPS	National Public Service
OPD	Organisation of Persons with Disabilities
PNG	Papua New Guinea
PNGADP	Papua New Guinea Assembly of Disabled People
UNAIDS	The Joint United Nations Programme on HIV/AIDS

# ENDNOTES

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- <sup>i</sup> Department for Community and Religion, Government of PNG, '[PNG National Disability Policy](#)', 2015,
- <sup>2</sup> See PNGADP website: <https://pngadp.weebly.com/>
- <sup>3</sup> UN, '[Convention on the Rights of Persons with Disabilities \(CRPD\)](#)', 2006.
- <sup>4</sup> Sally Baker, 'Disability Inclusion in Disaster Preparedness and Response: An Evaluation of Disability Inclusion in the Disaster READY Program in Fiji, Vanuatu, Solomon Islands, Papua New Guinea and Timor-Leste', June 2021, 69.
- <sup>5</sup> Kate Sutton, Seeta Giri, and Fanny Berg, 'Drawing On Our Diversity: Humanitarian Leadership', 2018.
- <sup>6</sup> CBM New Zealand, 'Inclusive Education & Rehabilitation Forum: Fostering Collaboration towards Inclusive Development in Papua New Guinea', 2018.
- <sup>7</sup> All interviews in the study; Yenas, A.M. '[The Importance of Strengthening Relationality: Experiences of Women Living with Visible, Physical Disabilities in Rural Papua New Guinea](#)', 2019; Kuzma, J, K Ramalingan, and P Karthikeyan. '[Traditional Beliefs and Care System Towards Persons with Disabilities in Papua New Guinea](#)', 2016; Yenas, A.M. '[What Are the Views and Experiences of Daily Life for Women Living with Visible, Physical Disabilities in Papua New Guinea?](#)', 2019; CBM New Zealand. 'Inclusive Education & Rehabilitation Forum: Fostering Collaboration towards Inclusive Development in Papua New Guinea', 2018.
- <sup>8</sup> CBM, '[What Are Barriers](#)', 2023,; Brigitte Rohwerder, '[Disability Inclusion](#)' (GSDRC, Institute of Development Studies, November 2015).
- <sup>9</sup> Department for Community and Religion, Government of PNG, '[PNG National Disability Policy](#)', 2015.
- <sup>10</sup> For more definition on Disability please see: CBM, '[What Is Disability](#)', 2023.
- <sup>11</sup> DFAT, 'Papua New Guinea Country Brief', 2023; The World Bank, 'The World Bank In Papua New Guinea', 2023.
- <sup>12</sup> DFAT, 'Papua New Guinea Country Brief'.
- <sup>13</sup> DFAT.
- <sup>14</sup> ADB, '[Papua New Guinea and ADB](#)', 2023,
- <sup>15</sup> 2009 Household Income and Expenditure Survey (HIES).
- <sup>16</sup> UN, 'Convention on the Rights of Persons with Disabilities (CRPD)'.
- <sup>17</sup> [Department of Personnel Management, Government of PNG, 'National Public Service Gender Equity & Social Inclusion \(GESI\) Policy](#)', 2014,
- <sup>18</sup> Interview PNGADP
- <sup>19</sup> A.M Yenas, '[What Are the Views and Experiences of Daily Life for Women Living with Visible, Physical Disabilities in Papua New Guinea?](#)', 2019, , 'The Importance of Strengthening Relationality: Experiences of Women Living with Visible, Physical Disabilities in Rural Papua New Guinea', 2019; Abel, M, M Johnston, and H McCulloch. '[Resilient WASH in the Islands Region of Papua New Guinea: Gender & Social Inclusion Baseline Summary](#)', 2022.
- <sup>20</sup> Baker, '[Disability Inclusion in Disaster Preparedness and Response: An Evaluation of Disability Inclusion in the Disaster READY Program in Fiji, Vanuatu, Solomon Islands, Papua New Guinea and Timor-Leste](#)'; Sally Baker et

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<sup>21</sup> UNAIDS, '[Papua New Guinea](#)', 2020.

<sup>22</sup> UNAIDS.

<sup>23</sup> A Kelly-Hanku et al., 'Kauntim Mi Tu Multi-Site Summary Report 2018: Key Findings from the Key Population Integrated Bio-Behavioural Survey Papua New Guinea' (Goroka, Papua New Guinea: Papua New Guinea Institute of Medical Research and Kirby Institute, UNSW Sydney, 2018), <https://www.aidsdatahub.org/resource/kauntim-mi-tu-multi-site-summary-report-2018-ibbs-png>.

<sup>24</sup> Global AIDS Monitoring 2020, '[Country Progress Report - Papua New Guinea](#)', 2020.

<sup>25</sup> Carol Kidu, '[A National Response to the HIV Epidemic in Papua New Guinea](#)', 2023.

<sup>26</sup> Interviews 1, 2, 3, 6, 15, 18.

<sup>27</sup> See J Kuzma, K Ramalingan, and P Karthikeyan, '[Traditional Beliefs and Care System Towards Persons with Disabilities in Papua New Guinea](#)', 2016, which found that: 'While culture plays a role in understanding and interpreting disability, it also creates barriers in certain aspects of people's lives. For example, the people of Okapa, Eastern Highlands, have a common belief that a child's disability is a form of punishment from bad spirits for the parent's sexual act in a forbidden area, while the people of Bunabun in Madang believe that transgression of taboos by a pregnant woman can result in her baby acquiring congenital abnormalities at birth'.

<sup>28</sup> See ILO Country Office for Pacific Island Countries, '[Disabilities and Decent Work in the Pacific: The Case for Disability Inclusive Employment](#)', 2012, which found that: 'The stereotypical view of disabled person being helpless discourages employers from recruiting people with such challenges. Even at the community level in the rural areas, people with disabilities are not included in income generating activities and related projects. They are also excluded from the decision-making processes at all levels of the community.'

<sup>29</sup> Interviews 2, 4, 10, 16.

<sup>30</sup> Department for Community and Religion, Government of PNG, 'PNG National Disability Policy'.

<sup>31</sup> Interviews 3, 4, 9, 11, 16.

<sup>32</sup> Interviews 19 and observations from researcher.

<sup>33</sup> This finding resonates with findings from case studies in Vanuatu and SI (CBM-HAG), and stresses the negative effects of diverse inclusion agendas of development partners with little space for OPDs to lead on the definition of their own priorities.

<sup>34</sup> From review of data collection tools used by 6 provincial OPDs.

<sup>35</sup> Interviews 3, 19.

<sup>36</sup> Interview 1.

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<sup>37</sup> From the learning and feedback session between HAG and CBM post completion of the case studies in Vanuatu and SI, see: Humanitarian Advisory Group et al., '[Organisations of Persons with Disabilities: Making a Difference in Vanuatu and Solomon Islands](#)', 2022.

<sup>38</sup> From researcher observations and experience visiting communities as part of the study.

<sup>39</sup> Interviews 3, 4, 7.

<sup>40</sup> Humanitarian Advisory Group et al., 'Organisations of Persons with Disabilities: Making a Difference in Vanuatu and Solomon Islands'.

<sup>41</sup> See findings from case studies, Humanitarian Advisory Group et al., 'Organisations of Persons with Disabilities: Making a Difference in Vanuatu and Solomon Islands'. On the role of OPDs in advocating for the rights of persons with disabilities.

<sup>42</sup> PNGADP Strategic Plans 2010–2014.

<sup>43</sup> See findings from case studies Humanitarian Advisory Group et al., 'Organisations of Persons with Disabilities: Making a Difference in Vanuatu and Solomon Islands'. On the role of OPDs in advocating for the rights of persons with disabilities.