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Papua New Guinea
Equitable Access
Research Report 2014

Papua New Guinea: Equitable Access Research Report

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1. Introduction

The Papua New Guinea (PNG) Equitable Access Research (EAR) project has significantly increased the understanding of Access to Mobility programme partners about the complex barriers that women, men and children face in accessing mobility device services; as well as the supports and resources that could help to overcome those barriers and facilitate access to mobility devices.

Three major themes emerged from the research related to gender, age and Government responsibility:

Gender: A key outcome from the EAR project was recognition that **while men and women both experience significant barriers to accessing a mobility device, the types of barriers they face are different.**

For men the key barriers identified were practical in nature, such as a lack of information or awareness and a lack of financial resources. Women also experienced those practical barriers however the most commonly identified barrier was gender related violence.

The facilitators identified also highlight the differences between men and women. The key facilitator identified for men is their ability to travel alone to a service provider, something that women feel unable to do. Their fear for their personal safety as well as their community or family expectation that women do not travel alone means that any visit to a service provider requires that male and female family members accompany them; increasing the cost and inconvenience of travel.

The second facilitator identified for men was related to the perceived qualities of men to be strong, confident and not shy; in contrast to women where the fourth most common barrier identified was that women are shy and lack confidence.

Perhaps of most significance was that while several facilitators were identified for men, no facilitators were identified for women. As the barriers that women face are not purely practical in nature, the more 'straight forward' solutions (such as assistance with the cost of travelling to a service provider) will not resolve their challenges.

Age: EAR participants identified that **people aged over 50 experience the highest level of difficulty in accessing a service**; with 92% of people indicating that it was hard or very hard for this group. In a similar way to gender related differences, two of the three top barriers identified for people aged over 50 were to do with sociocultural issues: older people are undervalued and lack support from their family.

Children were also identified as being reliant on their family to care for them and assist them to access services, however they were seen to benefit from the contrasting facilitator was that their parents love them. No facilitators were identified for people aged over 50 years.

Government responsibility: EAR participants recognise the value of being able to access consistent, local mobility device services. It was also clear that **people with a mobility disability feel that the responsibility to provide these services rests with the PNG government.**

Moving forward, the EAR project will enhance the ability of programme partners to: target vulnerable groups in the community and assist them to access services; advocate to and work with the PNG Government for appropriate resources to be allocated for the range of services required, and; support people with a disability and their representatives to educate community members about the rights of people with a mobility disability and the role that they can play in family and community life. This project will also serve to inform equitable mobility device service delivery in the Pacific Region.

The following report can be read in isolation; however the accompanying appendices will provide more in depth information about the EAR project design, implementation and results. All statistics reported have been determined to be statistically significant post removal of confounding factors.

2. Background

The PNG EAR project was a collaborative partnership between the PNG Assembly for Disabled Persons (ADP), the PNG National Orthotics and Prosthetics Service (NOPS), Motivation Australia and the Development Policy Centre at the Australian National University (ANU). The EAR project is part of a wider collaboration between NOPS, PNG ADP and Motivation Australia through the *Access to Mobility* programme (2012-2014) funded by the Australian Government through the Strongim Pipol Strongim Nesen (SPSN) programme.

The project's aim was to investigate the barriers and facilitators that exist in relation to accessing an appropriate mobility device service for people with a mobility disability in PNG. In order to achieve this, the EAR project was divided into two phases:

- **Phase one:** Questionnaires completed by local research teams with women and men with a mobility disability, and parents of children with a mobility disability in Central, Morobe, Western Highlands and Milne Bay provinces;
- **Phase two:** Focus groups conducted with women and men with a mobility disability and parents of children with a mobility disability in Central and Milne Bay provinces.

Overall 112 women, 104 men and the parents of 62 children completed the questionnaire in phase one of the project. 30 women and 11 men participated in the phase two focus groups; of those, 19 were representing a child with a mobility disability as the child's parent/guardian.

Research locations: Research locations were chosen that had established mobility device services and therefore the potential for people within that location to access a device. This ensured that people with a mobility disability who participated in the research could be referred to service providers if requested. The four locations were therefore centred around Port Moresby, Lae, Mount Hagen and Alotau. NOPS have established services in in Port Moresby, Lae, Mount Hagen and carry out outreach services to Alotau. Alotau also has a physiotherapy department at Alotau General Hospital which provides basic mobility devices. All four locations also have the support of an active branch of PNG ADP who were able to support the EAR project by providing local researchers and a contact network of people with a mobility disability and their families.

The two focus group locations were selected on the basis that they provided the most divergent situations of all four research areas. Central Province participants live in a predominantly urban setting with an established NOPS service centre; whereas participants from Milne Bay Province live in predominantly rural or remote settings with reduced local services and an annual outreach service from NOPS.

Key terms: The following terms were used frequently throughout the project and are defined as follows. Additional definitions are contained in Appendix A: Research Methodology, located in the full report.	
Mobility disability:	Any condition which may limit a person's ability to change and maintain body position, to walk or move from one place to another[1].
Personal mobility	The ability to change and maintain body position and walk and move from one place to another[2].
Mobility device:	Any device designed to assist personal mobility. Common examples include crutches, walking sticks, walking frames, wheelchairs, tricycles, scooters, orthoses (such as callipers, braces and splints), and prostheses (such as artificial legs).
Mobility device service:	Any service that carries out assessment, prescription, fitting, provision of a mobility device to a person who requires such a device; and ideally user training and follow up. PNG examples include: NOPS, hospitals, physiotherapy services.

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[1] WHO (2001), *The International Classification of Functioning, Disability and Health – ICF*, World Health Organisation, Geneva.
[2] WHO (2008), *Guidelines in the provision of Manual Wheelchairs in Less Resourced Settings,* joint paper by WHO, USAID and ISPO on the occasion of the 21st World Congress of Rehabilitation International.

3. Key results

As this study focused on the lived experience of people with a mobility disability, the responses are self-reported, communicating the perceptions of people with a mobility disability and their family members.

3.1 Key statistics from questionnaire (phase one)

Of those who participated in the questionnaire 75% were currently using, or had used a mobility device. 25% had never used a mobility device before.

Of those who were currently using, or had used mobility devices, wheelchairs (40%) were the most common device, followed by crutches (29%) and walking sticks (22%). Prosthetics (7%), walking frames (6%) and Orthotics (4%) were less commonly used devices[3].

The majority of participants who had used a mobility device thought it was either hard or very hard to get a device (57%). When asked to consider the difficulty for different groups of people, the following results demonstrate that it is considered hardest for people over the age of 50 years and women.
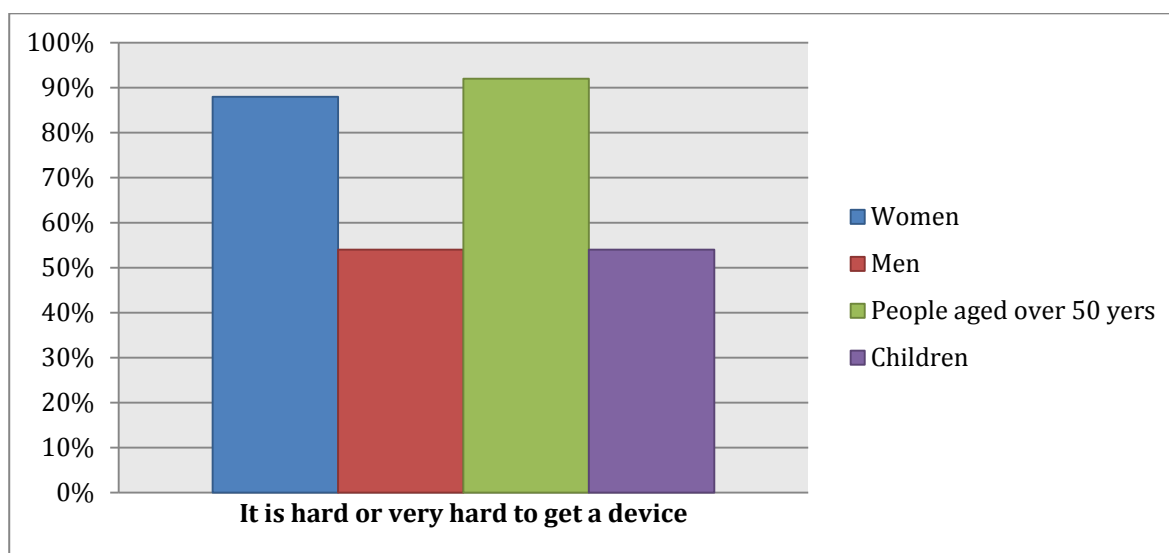
Of those who had never used a mobility device:
- 50% were living in Milne Bay, 27% were living in the Western Highlands, 14% were living in Central and 9% were living in Morobe Provinces.
- 87% report that they have never been offered a mobility device.
- Orthotics (37%) and walking sticks (28%) were the most common mobility devices that participants had heard of.

3.2 Barriers

The results of the EAR project demonstrate that people with a mobility disability in PNG experience multiple, complex barriers to accessing appropriate mobility devices. These barriers can be broadly categorised into two types: practical and sociocultural.

Practical barriers: Practical barriers include *service access prerequisites* such as: people with a mobility disability knowing that mobility devices exist and that these devices can reduce the impact of disability; knowing that there are services available and how to access them, or; availability of a local service provider who has a stock of appropriate mobility devices.

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[3] Participants could indicate more than one device.

Practical barriers also include *access to resources* such as: accessible transportation; money to pay for the costs associated with accessing a device (transportation, lost working time to attend appointments, food and accommodation), or; money to purchase the device.

Sociocultural barriers: Sociocultural barriers include *attitudinal* barriers – namely the perceived lesser value of people with a mobility disability can experience from their family and community in relation to their ability to contribute to society, or; the perceived low worth of mobility devices.

Attitudinal barriers also include the underlying low value and position attributed generally to women, elderly people and children within the family or community structure. This double disadvantage that women, elderly people and children with a mobility disability experience was a key theme to emerge from the research.

Sociocultural barriers also include *safety and security* issues for women travelling to a service. For many women the need to travel with several additional escorts creates a situation where they are unable to access services due to the lack of availability of male and female family members to accompany them.

Gender related differences in barrier identification

Along with the perception that it is harder for women to access a mobility device compared with men, the identified barriers are also different. The barriers identified for men are practical, such as information and finances. For women, the primary identified barrier is related to their status as a woman and gender based safety concerns. In addition to this 19% of participants identified that women are shy and lack confidence, which creates a barrier to accessing a mobility device service.

Key barriers for men: Lack of information/awareness (37%); the financial costs associated with accessing a service (27%), and; the financial cost of the device (23%).

Key barriers for women: Gender related violence and lack of safety (25%); lack of information/awareness (23%), and; the financial costs associated with accessing a service (22%).

Age related differences in barrier identification

A key finding of the research was the level of difficulty that people aged over 50 years experience in accessing a mobility device service. 92% of participants reported that it is hard or very hard for people aged over 50 years to access a device – the highest level of any group.

Key barriers for people aged over 50 years: Their own physical limitations that prevent them from accessing a service (47%); older people are undervalued (25%), and; lack of family support (17%).

Key barriers for people aged 18-30 years: The financial costs associated with accessing a service (23%); the financial cost of the device (22%), and; lack of support from family and friends (18%).

Key barriers for people aged under 17 years: The financial costs associated with accessing a service (27%); children's reliance/dependence on others to access a service (25%), and; the financial cost of the device (21%).

3.3 Facilitators

The facilitators identified by participants in general were those things that assisted the person with a mobility disability to overcome barriers to accessing a mobility device.

> **Key facilitators:** Knowledge and awareness about what services are available (40%); transportation and accommodation assistance (22%), and; good contacts/connections between service providers and the community (as well as between service providers) (16%).

Gender based differences in facilitator identification

Facilitators for accessing a service also highlight the perceptions of the differences between men and women. Facilitators for men include: Ability of men to travel alone to a service provider (33%); personal quality of men to be strong, confident and not shy (25%), and; that men seek help and have access to information (23%). Participants did not identify any facilitators for women

Aged based differences in facilitator identification

While participants recognised that children are reliant on family members to assist them (and note it as a potential barrier), the key facilitator identified by 52% of participants for children under 18 years of age is a supportive family. For adults (18-30 years) facilitators included: their ease of travelling around (44%); their quality of youth (28%), and; supportive family and friends (18%).

As for women, no facilitators were identified for adults aged over 50 years.

3.4 Service provision

Two major themes relating to service provision emerged from the research: firstly the responsibility of the PNG government in the provision of mobility device services; and secondly the need for more communities to be able to access services.

Research participants recognised and appreciated efforts of international aid organisations, church based charity groups and community organisations in supporting people with a mobility disability to access services. However, responses carried a clear message that the responsibility for mobility device provision rests with the PNG government. Concurrently the role of people with a disability, their family and representatives is to advocate for service provision and educate the politicians, government departments and service managers about the *need* for services and the importance of supporting people with a disability and their families.

The isolated nature of many of PNG's island and mountain communities was recognised as a significant barrier to accessing services. Building the skills and knowledge of community members to provide a service, or centralised services providing community visits was viewed as a crucial step in both raising the awareness of the availability of mobility devices and in providing equitable access to services.

Non-government service provision: Churches, charitable or political groups that provide mobility devices were considered by participants to lack clarity about eligibility to receive the device. It was reported that people with a mobility disability and their families can be left feeling stressed and anxious about whether or not they will receive a device. Devices could also be a single type and size, leading to some people using devices that are not appropriate to their needs.

3.5 Additional themes

While the EAR project focused on access to mobility devices, some additional information was shared with researchers. This included concerns raised by mothers of children with a mobility disability about the safety and well-being of their child. Protecting their child from physical and sexual abuse by family

and community members was a constant concern for some mothers, and resulted in a reluctance to leave them at home without supervision. Mothers also described their concern for other children with a mobility disability who were neglected by their family and community; reportedly through a lack of finances or lack of understanding about how to care for a child with a disability, lack of family support and a lack of hope for the future.

Some parents expressed that their decision to continue to care for their child with a disability was not supported by other family members. The perceived lack of support for their children by family and community was stressful, adding to their burden of care.

4. Limitations of the research

4.1 **Mobility devices:** This research was not intended to identify the appropriateness of the mobility devices used by participants and therefore no qualifications regarding the suitability of equipment that participants had accessed are made.

4.2 **Mobility device need:** The research design did not enable a determination to be made as to whether or not those who self-identified as having a mobility disability needed a mobility device or not. Therefore an assumption was made that those who have self-identified as having a mobility disability would benefit from the provision of an appropriate device.

4.3 **Distance from service:** EAR participants for the questionnaire were selected from within a 20-kilometre radius of the local NOPS service provider, or 50 kilometres from Alotau General Hospital. This has restricted input from those people with a mobility disability who live further from service providers where issues such as lack of information, isolation and limited access to roads and transport are likely to be more pronounced.

4.4 **Sample group:** Those selected for participation in the EAR questionnaire were primarily sourced through communities, organisations and personal contacts of the interviewers. All EAR data collectors had accessed disability services and were linked though the local disabled persons organisation.

5. Conclusions

- **Mobility device services are highly valued:** People with a mobility disability in PNG value access to a local, consistent, government funded mobility device services.

- **The PNG Government are the appropriate body to be responsible for mobility device service provision:** The PNG Government is viewed by people with a mobility disability and their families as having the key responsibility for providing mobility device services – as well as other financial or service based supports. International aid organisations, charitable organisations are seen as important partners to support the development of such a service, however ultimate responsibility rests with the government to coordinate and legislate this process.

- **Lack of information is a significant barrier:** Lack of information or incorrect information is a significant, overarching barrier in accessing services for women, men, girls and boys with a mobility disability. Without accurate information about the existence of mobility devices; the presence of mobility devices within the service provider network; and the steps required to access a device; a person with a mobility disability and/or their family is far less likely to access appropriate mobility devices or services.

- **Information spreads through word of mouth:** Information is largely shared throughout families, communities, villages and districts through conversations, community meetings and public announcements. This information can be accurate – leading to increased access of services and supports. This information can also be inaccurate which leads to confusion and misunderstandings for clients and their families.

- **Lack of appropriate transportation is a significant barrier:** The cost and/or inaccessibility of public transport is a significant barrier for people who need to access mobility device services.

- **Women with a disability are doubly disadvantaged:** Women and girls with a mobility disability face additional gender-based barriers to accessing services including fear of attack when travelling alone, lack of information and lack of independent resources. Women and girls with a mobility disability are disadvantaged by their status as a woman and their status as a person with a mobility disability.

- **If there is no local service – it's much harder to get a device:** Many people live in locations far from formal mobility device services in locations that are several days walk, boat or Public Motor Vehicle (PMV) ride from provincial capitals.

- **It is harder for older people:** Compared to men and women in general, older people with a mobility disability find it more difficult to access mobility devices and services. Older people often lack family support to access a mobility device service as older adults can be perceived as a lesser priority.

- **The amount of family and community support for people with a mobility disability is an important factor:** People with a mobility disability are often reliant on family members support – especially children, elderly people and those with moderate to severe disabilities. 63% of people who were using, or had used a mobility device had received assistance from a family member to access the device. Family and communities can provide people with money for transport, physical assistance to get to a service, and general care for their health and wellbeing. Without such support a person with a disability may be excluded from accessing health and education services and become isolated.

- **Information needs to be provided in multiple-languages:** While Tok Pisin is considered a 'common language' there are many local variances and people in village communities – especially women and elderly people, who do not speak it.

- **Doctors and physiotherapists are key sources of information for the community:** Aside from friends and family, doctors and physiotherapists are the key groups contacted by people with a mobility disability and their families.

6. Recommendations

6.1 Access to Mobility programme partners

1. **Community awareness campaign:** Building on the community 'word of mouth' network, community awareness campaigns could focus on both general issues – such as the rights of people with a disability, and specific information – such as how to contact a mobility device service provider.

2. **Develop awareness raising materials in a broad range of language categories:** Design and distribute printed materials (posters, pamphlets) with simple language or limited use of language that can be translated easily into local dialects.

3. **Support and empower people with a mobility disability to be active in raising awareness:** Utilise the individual stories of people gaining independence through mobility device service provision to increase community awareness about mobility device services.

4. **Raise awareness with members of Local Level Government and National Parliament:** Implement a comprehensive awareness raising campaign aimed at members of Local and National Government.

5. **Advocate for increased support for people with a mobility disability and their families to the National Parliament:** Issues to be raised include: the financial security of people with a mobility disability and their families, service provision to isolated and rural locations, and accessibility of public transport.

6. **Community based rehabilitation or community outreach:** Partners should review the possibilities for some services to be available in the community through developing and extending NOPS services or networking with community organisations already present at a community level.

7. **Carry out referral network training for doctors and hospital services:** Raise awareness of medical personnel about the availability of mobility device services, and how to refer patients to these services utilising a Referral Network training package, posters and pamphlets to develop stronger referral networks and pathways.

8. **Build links with physiotherapy services: Increased dialogue and cooperation between NOPS and physiotherapy services** will increase the number of and improve the quality of early referral for people with a mobility disability. Improve communication and referral networks between physiotherapists and mobility device service providers.

9. **Increase the number of national physiotherapists trained in wheelchair service delivery:** Integrate the WHO Wheelchair Service Training Package into the PNG Physiotherapy degree programme in order to increase the numbers of trained personnel in PNG with wheelchair service provision knowledge; and

10. **Enhance signs and notices for NOPS services:** Clear signage and direction notices for NOPS services would increase visibility of the service for clients and their families, resulting in increased awareness.

6.2 Motivation Australia – recommendations for future programmes

11. **Information and awareness strategies:** Include a whole of community awareness raising strategy focusing on how people can access mobility device services.

12. **Addressing the practical barriers to service provision:** Work with local partners to identify community organisations, government services, charities and church groups who can assist people with a mobility disability and their families to overcome the practical barriers to accessing a service such as physical accessibility and cost of transportation.

13. **Gender based targets:** Incorporate gender based targets as part of the monitoring and evaluation of service provision equity; and consider partnerships with non-disability related organisations who have expertise in reducing the barriers for women and girls to participate in community life, access services or seek information.

6.3 Further research

14. **Quality of mobility devices:** Collecting information about the appropriateness of the mobility device accessed by people with mobility disabilities (not collected during this study), would provide further important information regarding the quality of mobility device provision in PNG.

15. **Impact of living in an isolated village:** Participants in the EAR project lived within 20 kilometres of a NOPS service (or 50 kilometres in the case of Alotau), which are based in cities and towns. Locating and talking with people with a mobility disability in isolated locations several days walk from service centres may produce a different picture of the barriers to services.

16. **Mobility device ownership:** That future studies define what constitutes "access to" or "use of" a mobility device, and include additional research questions investigating whether participants who had (or have had) a mobility device shared the same device with other family or community members or not, in order to better understand the issue of device ownership and sole use.

7. Acknowledgements

Motivation Australia, PNG ADP and NOPS would like to thank all of the women and men with a mobility disability, parents of children with a mobility disability that participated in this research project. Thank you for trusting us with your experiences, stories and insights into life for people with a mobility disability in Papua New Guinea.

Congratulations and well done to the local team of researchers who conducted this project. Your enthusiasm and commitment to listen to and share the stories of others made this research possible.

8. Authors

This report was prepared by Motivation Australia's Lauren Flaherty (Senior Clinical Coordinator), and Cristy Wilson (Consultant Occupational Therapist). The report was reviewed by Motivation Australia's Kylie Mines (Chief Executive), Ray Mines (Director of Design and Innovation) and Australian National University's Dr Dinuk Jayasuriya.

If you would like more information about the EAR project, or you would like a copy of the full report please contact Motivation Australia (admin@motivation.org.au).

9. Research background

9.1 Research question

What barriers and facilitators exist in relation to accessing an appropriate mobility device service for women, men and children with a mobility disability in Papua New Guinea?

9.2 Populations targeted

Women, men and children with a mobility disability living in the Central, Milne Bay, Western Highlands and Morobe Provinces of PNG.

9.3 Expected outcomes

- Improved understanding of factors impacting equitable access to mobility device services in PNG.
- Development of practical strategies for equitable mobility device service delivery, which will inform disability inclusive development in PNG and other contexts.
- Increased awareness amongst stakeholders of the barriers women, men and children may face in accessing mobility device services.
- Enhanced capacity, knowledge and empowerment of PNG ADP and members enabling effective advocacy for the right to mobility for women, men and children with a mobility disability in PNG.
- Enhanced capacity of NOPS and other mobility device services to deliver effective and equitable services through the implementation of practical strategies.

9.4 Research objectives

1. To identify factors that influence equitable access to mobility device services in PNG.
2. Identify practical strategies that can be implemented in PNG (and other Pacific countries) to enable equitable service delivery for women, men and children with a mobility disability.
3. Highlight to NOPS and the PNG ADP any issues relating to inequity in service provision in order for the development of specific strategies to enhance mobility equipment provision and reduce inequities by the organisations.

9.5 Selection criteria – Questionnaire participants

Inclusion criteria: Participants were required to either:
   a) Have had physical difficulty[4] mobilising for more than six months, and be aged 18 years and over, or;
   b) Be the parent of a child (0 – 18 years old) with physical difficulty mobilising for more than six months.

Participants also had to reside within one of the following provinces:
* Central Province (Port Moresby)
* Western Highlands Province (Mount Hagen)
* Morobe Province (Lae)
* Milne Bay Province[5] (Alotau)

9.6 Selection criteria – focus group participants:

Inclusion criteria: Focus group participants were required to have a mobility disability, or be the parent of a child with a mobility disability and reside within either:
* Central Province (Port Moresby)
* Milne Bay Province (Alotau)

The two focus group areas were selected on the basis that they provided the most divergent situations of all four research areas. While Central Province participants live in a predominantly urban setting and there is the presence of a full NOPS service centre, participants from Alotau live in predominantly rural or remote settings with only the presence of a fledgling satellite NOPS.

10.   Research methodology

Refer to *Appendix A – Research Methodology* (located in the full report) for an in-depth account of the research protocol; including the questionnaire form; research definitions; and information and consent forms used.

10.1   Methods

The research design utilised a mixed methods approach incorporating quantitative, quasi-qualitative and qualitative methods in order to maximise the quality and usefulness of findings in relation to service and policy development. Questionnaires and focus groups were used to generate the desired data.

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[4] Participants self-identified as having a mobility difficulty.
[5] A different research area parameter was set in Milne Bay Province (Area 8) due to the peninsular geography of this region.

10.2   *Data management and statistical analysis*

Prior to commencement of phase one of the EAR project, data collectors attended a five day training/pilot testing workshop held in Port Moresby in February 2013. Please refer to *Appendix D* (located in the full report) for further details relating to workshop participants and content. Participation in this workshop provided the data collectors, all of whom had a mobility disability, with the skills required to conduct the research.

Questionnaire data was entered into databases to enable statistical and thematic analysis of findings. Following completion of questionnaires and focus groups, specific statements/responses were analysed and categorized into clusters of meaning that represent the phenomenon of interest. Thematic content analysis was conducted whereby rigorous and systematic analysis of the data occurred to develop concepts and categories that emerged from the words.

10.3   *Ethics approval*

Ethical approval was granted by the Human Research Ethics Committee, at the Australian National University, Canberra, ACT.

11.   Gender, age and location targets

11.1   *Gender and age*

In order to learn more about how gender and age changed an individual's ability to access a mobility device; a target number of respondents based on gender and age were set. These targets were set based on the assumption that women and children are less likely to access an appropriate mobility device than men.

Due to local logistical barriers (transportation; weather; terrain and complications related to the health and disabilities of the EAR teams) the overall number of participants was less than targeted. 112 women were interviewed instead of 200, and 62 parents were interviewed instead of the target of 120.

	Women	**Men**	**Children**[6]
Target number	200	80	120
Achieved number[7]	112	104	62
Target percentage	50%	20%	30%
Achieved percentage	40%	38%	22%

11.2   *Province and distance from service*

The four provinces included in the EAR were Central, Morobe, Western Highlands and Milne Bay. NOPS services are established in Port Moresby (Central Province), Lae (Morobe Province) and Mount Hagen (Western Highlands Province). Alotau (Milne Bay Province) does not have a NOPS service established; however NOPS are supporting wheelchair service provision through the local physiotherapy department, and with annual out-reach visits by the Port Moresby team.

For Central, Morobe and Western Highlands Provinces participants were selected who lived within 0-5 or 10-20 kilometres from NOPS. For Milne Bay, participants were selected who lived within 0-5 or 20-50 kilometres of Alotau General Hospital Physiotherapy (PT) department. Milne Bay's target area was adjusted to allow for the peninsular geography of the region.

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[6] For the 0 – 17 age group, parents answered on their child's behalf.
[7] One child participant did not indicate their gender.

The defined 0-5 and 10-20 (or 20-50 for Alotau) kilometre areas were set to determine if the distance that someone lived from a mobility device service (either NOPS or PT department) impacted on participants perceived experiences in relation to accessing a mobility device and service.

Province	0-5 kms	10+ kms	Total
Central	38	43	81
Morobe	31	2	33
Western Highlands	39	50	89
Milne Bay	6	68	74
Total	**114**	**163**	

11.3 Focus group participants

A total of six focus groups were conducted in June 2013. These groups consisted of the following participants:

Port Moresby Focus Groups	Participants
Men with a mobility disability	3
Women with a mobility disability	9
Parents of children with a mobility disability	9
Alotau Focus Groups	**Participants**
Men with a mobility disability	4
Women with a mobility disability	6
Parents of children with a mobility disability	10
Total	**41**

12. Literature review

A literature review was conducted in October 2012 to inform the design of the EAR project. Please refer to *Appendix B* (located in the full report) for the complete literature review and reference list.

12.1 Key findings

- Globally more than one billion people live with some form of disability, which corresponds to approximately 15% of the world's population (WHO, 2011b).

- 0.5% of the population in less resourced settings require orthoses or prostheses (WHO, 2005b).

- Approximately 1% of the population with disabilities in developing countries require a wheelchair (ISPO/USAID/WHO, 2006).

- The number of people with disabilities is projected to increase because of the ageing population and the global increase in chronic conditions, especially common non-communicable diseases such as diabetes, stroke and cancer (WHOa 2011, p.13).

- The majority of people with disabilities living in less-resourced settings have little or no access to devices that could contribute to improving their life situation and help many to a more independent life (Øderud and Grann, 1999).

- Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities. People with disabilities experience additional barriers in accessing services that

many of us have long taken for granted, including health, education, employment, transport and information (WHO 2011b, p. xi).

- Disability can result in poverty through persons with disabilities being prevented from full participation in the economic and social life of their community (Eide and Øderud, 2009). Excluded in this way, the consequences are often extreme, leading to isolation, dependence, injustice, illiteracy, low self-esteem, unemployment, poverty and poor health (Mines, 2008; WHO, 2008).

- Mobility devices can have significant impact on the level of independence and participation people with disabilities are able to achieve (WHO, 2011), and reduce the need for formal support services, as well as reduce the time and physical burden for caregivers (Allen et al., 2006).

- Mobility devices are often supplied without consideration of the need for associated services; including individual assessment, selection, fitting, training and follow-up to ensure safe and efficient use. Such omissions impact significantly on outcomes, often resulting in incompatibility with the local environment and resulting in abandonment or secondary complications, which can ultimately shorten life expectancy (Borg, Lindstrom, and Larsson, 2011).

- In many instances inappropriate wheelchairs have caused physical harm through the development of secondary problems such as life threatening pressure sores or debilitating physical deformities (Wheelchair Consensus Symposium 2008, p. 2).

- For people with a mobility disability, provision of a mobility device which meets their physical, lifestyle and environmental needs can vastly improve health, social and economic wellbeing. However, there are many barriers preventing accessing to a mobility device which meets needs. These include a lack of appropriate quality devices, and a lack of staff trained to manage the provision of mobility device.

- Barriers to accessing an appropriate mobility device and service include: lack of leadership and governance; financing and affordability; adequate service delivery; lack of adequately trained personnel; production to meet demand; awareness, cultural and social barriers; as well as the physical environment (WHO/USAID, 2011).

- Cost, lack of services in the area, transportation, distance, services no longer being helpful, and dissatisfaction with the services are all commonly cited barriers to accessing a healthcare service (WHO, 2011).

- Affordability is the primary reason people with disabilities did not receive needed healthcare with transport costs also ranking highly as a barrier in low-income countries, across gender and age groups (WHO, 2011).

- People more acutely affected by limited access to services are women, children, minorities, and persons with certain types of disabilities. Working to remove barriers to access services for these population groups increases the chance that persons with disabilities will be able to fully benefit from the service (Handicap International, 2010). Improving the quality of service without improving access to the service does not necessarily assist in improving living conditions. The social determinants which impact on a person's ability to access a service must also be addressed.

- Research conducted by Morris, Sharma and Sonpal (2005) revealed that non-disabled people were not insensitive to the issues faced by persons with disabilities, but largely ignorant of them. Increasing awareness of the needs of people with a disability lead to increased willingness to encourage those with disabilities to participate in society.

PNG specific research:

- According to the 2009 PNG National Policy on Disability (PNG NBDP, 2009), it is estimated that up to 15% of a developing country's population will have some kind of disability. Thornton and Pirpir's 2008 research found much higher prevalence rates, particularly in the urban highlands.

- The threat of gender-based violence impacts on a woman's ability to: move freely in the community; use public transport; access health and education services; and to travel to the market or workplace (Amnesty International, 2006). Coupled with a mobility disability, the impact of such exclusion on the health of a woman is profound.

- Women's health problems are related to the constant struggle of their daily circumstances, which includes unequal social relationships, economic constraints, workload demands and regular abuse and violence. For older women, lack of mobility, limited financial resources and lack of social support were the main factors inhibiting older women's access to health services (Hinton and Earnest, 2010a).

- Cohen (1998 cited in Hinton and Earnest, 2010) suggests, while many of the social determinants of health are the same for women and men, the interaction of these determinants with gender result in different experiences of health and illness for women and men.

Key findings of the literature review instrumental in developing the research protocol:

- Key findings stress the importance of using qualitative research methods to unearth the socio-cultural factors which impact on access to services for people with a disability.

- A participatory methodology allows for exploration of local knowledge and perceptions, whilst empowering people with disabilities and promoting their ownership in the research process (Cornwall and Jewkes 1995, cited in Whitzman and Pearce 2011, p. 10).

- When collecting data, Handicap International (2010) recommends identifying the main barriers to accessing services for persons with disabilities in relation to: services, professionals, barriers due to the cost of services; lack of information regarding existing services; referral procedures; 'passivity' of users or 'fatalism' about their situation; the general public's negative view of disability; cultural barriers; and physical and architectural barriers.

- Morris, Sharma and Sonpal (2005) indicate the need to clearly communicate the purpose of the research to the community; and the need to understand disability issues from women's perspectives given the double discrimination faced due to both their gender and impairment.

- The World report on disability (WHO, 2011) recommends using qualitative research to investigate the full range of barriers which impact on access to a service for people with a disability. Also it is important to analyse the needs, experiences, and views of people with disabilities to identify gaps and priorities to reduce health inequalities and plan improvements for access and inclusion.

13. Key data

13.1 Participants

Of the 278 people who participated in phase one of the EAR project:
- 75% either had or had used a mobility device;
- 25% had never used a mobility device, despite identifying as having difficulty mobilising;
- The self reported conditions impacting on a participants' ability to move around ranged from congenital conditions (24%), generally unwell (23%), acquired brain injury (18%), pain (14%), amputation (9%), trauma or injury (8%), weakness/numbness (7%), polio (5%), vision impairment (5%) and arthritis (5%);
- The mobility devices used by participants' included: wheelchairs (40%), crutches (29%), walking sticks (22%), homemade devices (15%), prosthetics (7%) and orthotics (4%).

Of those people who had used or were currently using a mobility device:
- 27% received a device from hospital;
- 25% from a mobility device service;
- 16% from family and friends;
- 15% had a homemade device.

Of those people who did not have, or have never had a mobility device:
- 50% were living in Milne Bay province.
- 27% were living in the Western Highlands province.
- 14% were living in Central province.
- 9% were living in Morobe province.
- 87% had never been offered a device.
- 11% had been offered a device.
- 2% were unsure of whether they had been offered a device.

13.2   *Barriers and facilitators to accessing mobility device services*

Gender related barriers: The five most common barriers identified for men and women:

Barriers identified for men	Barriers identified for women
1. Lack of information & awareness 2. Costs associated with accessing a service[8] 3. Cost of purchasing the device 4. Location of the service 5. Lack of suitable transport options	1. Gender related safety factors/violence towards women 2. Lack of information & awareness 3. Costs associated with accessing a service[8] 4. Women are shy and lack confidence 5. Cost of purchasing a device

Gender related facilitators: The five most common facilitators identified for men and women:

Facilitators identified for men	Facilitators identified for women
1. Ability of men to travel alone to a service 2. Men are strong, confident and not shy 3. Men seek help & have access to information 4. Men are prioritised & given more opportunities 5. Men are brave fearless & strong willed	No facilitators were identified by participants

Age related barriers: The five most common barriers identified for children, adults and older adults:

Barriers identified for children 0 – 17 years	Barriers identified for adults 18-30 years
1. Costs associated with accessing a service 2. Reliance & dependence on others 3. Cost of the device 4. Lack of information 5. Lack of family support	1. Cost of the device 2. Costs associated with accessing a service 3. Lack of support from family & friends 4. Inaccessible public transport & roads 5. Location of service

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[8] Costs of accessing a service include the cost of transportation, accommodation, meals and lost income/productivity while attending appointments.

| Barriers identified for people aged 50+ |
|---|
| 1. Physical limitations |
| 2. Older people are undervalued |
| 3. Lack of family support |
| 4. Lack of information and awareness |
| 5. Costs associated with accessing a service |

Aged related facilitators: The five most common facilitators identified for children, adults and older adults:

Facilitators identified for children 0 -17 years	Facilitators identified for adults 18 – 30 years
1. Supportive family	1. Ease of travelling/moving around
2. Due to their young age	2. Because of their age/youth
3. Parents & family love them	3. Supportive family & friends
4. They have accessible transport options	4. Supportive community
5. Community is supportive of children	5. Young people are prioritised
Facilitators identified for people aged 50+	
No facilitators were identified by participants	

13.3   Impact of gender

- A female is 12% more likely than a male to state that they have never used a mobility device.
- A female is 17% more likely than a male to state they have never asked for help to access a mobility device.

When asked "How easy is it to get a mobility device?" for a variety of different demographic options (gender and age) participants responded:
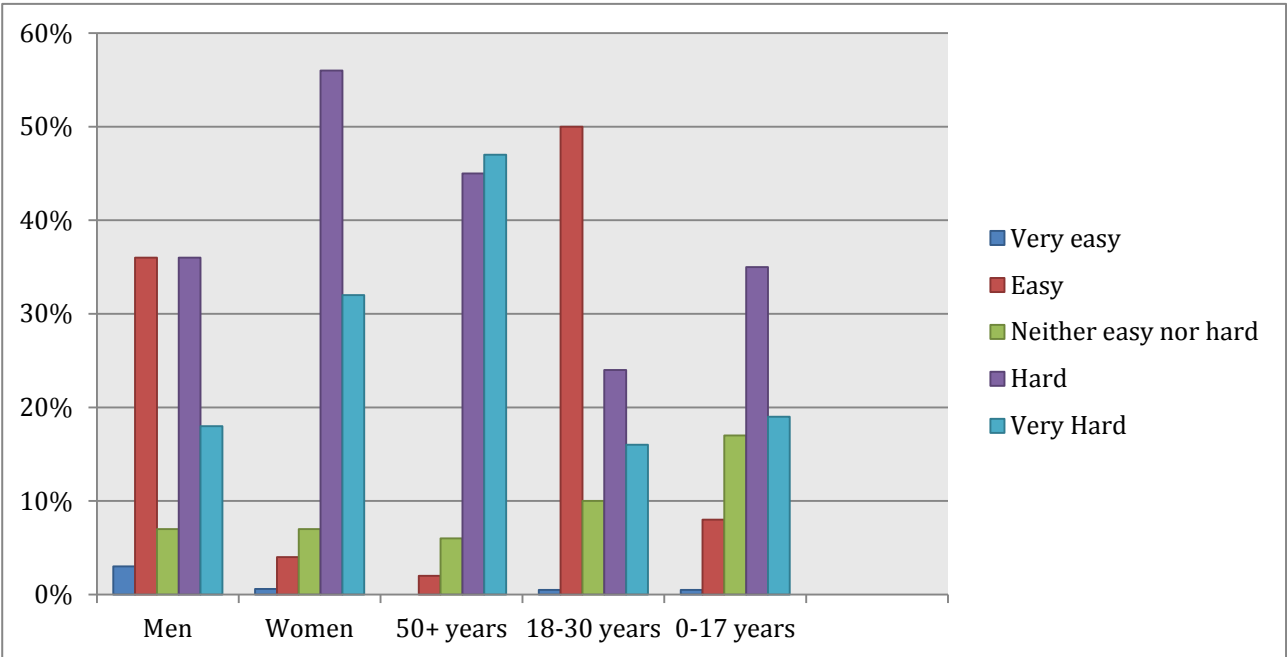
13.4   Impact of location

Compared to people who live in Central Province: People in Western Highlands are:
- 13% more likely to have never used a mobility device
- 16% more likely to state where they live makes it harder to get a mobility device

Compared to people who live in Central Province: People in Milne Bay are:
- 46% more likely to have never used a mobility device
- 26% less likely to find it easy to get a mobility device
- 52% more likely to answer that they have not asked for help regarding their mobility device

Compared to people who live in Central Province: People in Morobe are:
- 33% more likely to have never used a mobility device
- 54% less likely to find it easy to get a mobility device
- 49% more likely to state where they live makes it easier to get a mobility device

Relative to a person who lives within 0-5 kilometres of NOPS: People who live more than ten kilometres from a NOPS service or the Alotau PT department are:
- 15% less likely to know how to get a mobility device;
- 27% less likely to state that it is easy to get a mobility device.

13.5   Assistance

When asked "Have you ever asked for help regarding your mobility disability?"
- 73% of people have sought assistance for their mobility disability;
- 87% of people who have had a device received assistance to do so.

When asked "who did you ask for help?"
- 41% of people asked a doctor;
- 13% approached family members and friends;
- 11% asked a physiotherapist for help.

When asked "Who assisted you to get your mobility device?"
- 63% received assistance from friends or family
- 12% received assistance from doctors
- 7% received assistance from mobility device services
- 5% received assistance from physiotherapists
- 5% received assistance from aid/health posts
- 4% received assistance from church groups
- 4% received assistance from charities.

13.6   Knowledge about how to access mobility devices/services

How much do you know about how to get a mobility device?
- 80% of people felt they had no information or knew very little about how to get a mobility device;
- 20% of people felt that they knew some or a lot of information about how to get a mobility device.

What type of information exists relating to mobility devices?

Key types of information
Word of mouth – people telling me about it
None – no information exists
Different types of media (newspaper, radio, TV, posters, pamphlets)
Hospitals and Health posts
Awareness campaigns

How do people currently find out about accessing mobility device services?

Key sources of information
Word of Mouth – people telling me about it
Hospital and Health posts
None (people are unable to find out any information)
Awareness campaigns
Different types of media (newspaper, radio, TV, posters, pamphlets)

13.7   Raising awareness

The following responses are suggestions made by participants in relation to the most effective means for raising awareness about mobility devices and services in the community.

Awareness raising strategies
Community awareness campaigns
Posters/pamphlets
Mobile phone
Radio
Newspaper
TV
Service provider community visits
Word of mouth

Of the 25% of participants who had never accessed a mobility device, 85% report that they know 'very little' or 'nothing' about how to get a mobility device. 18% knew 'some' and 2% knew 'a lot'. Identified sources of information include:

- Seeing others using mobility devices
- Talking to EAR data collectors
- Hospitals
- Word of mouth

14. Focus groups

The focus groups were an opportunity to talk to people with a mobility disability and their families, and learn more about their perceptions, experiences and ideas around mobility devices and service provision. This was a valuable addition to the research results, and allowed researchers to gain more insight into the way the barriers and facilitators are experienced.

Analysing the data: Each focus group was conducted, recorded, transcribed and reviewed by two researchers. A third researcher who had not been present during the focus groups reviewed the transcriptions for accuracy. An analysis of the data gathered during the focus groups provided the EAR project with five themes and 27 topics.

Theme	Topics
Information and awareness	There is a lack of information about mobility device services.
	Raising awareness through multiple media channels is a good way to disseminate new information.
	Awareness campaigns should make use of the community word of mouth communication network.
	Printed materials are an important method of awareness raising and sharing information.
	Include people with a disability and their families in awareness raising activities.
	Awareness raising activities should focus on the rights and value of people with a disability.
Location	Where people live can prevent them from accessing a service.
Socio-cultural beliefs and attitudes	Discrimination of people with a mobility disability is a barrier to community participation and access to mobility device service provision.
	Misinformation about the cause of disability can reduce the support provided to people with a disability and their families.
	Children with a mobility disability can experience violence and neglect from family and community members.
	Lack of family support is a barrier for people with a mobility disability.
	The 'burden of care' can make it difficult for people to assist their family members the way they would like to.
	Gender related discrimination and violence is a barrier for women with a mobility disability.
	People with a mobility disability can contribute to their families and communities.

Theme	Topics
Service provision	Access to appropriate mobility device service provision is valued by people with a mobility disability.
	The PNG Government is the appropriate organisation to take the lead in wheelchair service provision.
	Local community access to services is essential.
	Changing eligibility criteria of some charity and church based service providers can confuse people about their right of access.
	Mobility devices lead to independence and visibility.
	NOPS is a valued service provider.
	Role of disabled person's organisations is to advocate on behalf of people with a mobility disability to government and service providers.
	Government responsibility for services and support for people with a disability and their families
	Corruption and fraud reduces the confidence of people with a mobility disability in the government system.
	Lack of support from service providers and government is a barrier to accessing services.
Prerequisites for accessing a mobility device service	Transport is a key barrier to accessing services.
	Gender based transport issues
	Financial barriers

14.1 Information and awareness

There is a lack of information about mobility device services: A lack of information is a significant barrier for people with a mobility disability to access services. Without information about where to go to get a service; what kind of service will be provided; who is eligible for the service, and; what the assistive device costs, people with a mobility disability are unable to access services.

"I think first of all we need to know the information that, that service will be provided. Once we found that I can manoeuvre and negotiate my way around..." (male POM[9] participant).

There "…is a lack of awareness, many people in the remote area where I stay, they have no idea about this. Even including myself, even I was a nursing by professional, I have no idea about these things… they are eager to use these things, but because they have no idea about, that they don't know whether there, there are things available for them" (female POM participant).

"we were really caught by surprise because we been out having physiotherapy and back and to the ward and back and just NOPS is just a few steps away and no doctor, no professional or specialist has ever directed us to NOPS…until right now, I never heard of it, I never been to that place. Never. And I think, I'm one very unfortunate parent, not knowing that place"

"I think basically it's just a lack of information. We have people who were in the hospital trying to help but they have no information about NOPS… I mean just imagine working in a hospital just a few minutes' walk away from NOPS and not knowing what it is, it's just lack of information that's available" (parent from POM group).

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[9] POM – Port Moresby

Raising awareness through multiple media channels is a good way to disseminate new information: Participants recommended that all forms of media are used to provide information to the towns and villages across PNG. Due to the variety of media access, the 'media' includes television, mobile phones, newspapers mainstream and short wave radio broadcasts.

> "Yes they should have awareness, and if they can have programmes on MTV, a very special programme for disabilities to go on. Because I believe that everyone across the board watches TV. And should be on the radio, as a Tok Save programme too, for those, so that the network can reach out to everyone that does not know what our needs" (parent from POM group).

> "Apart from information booklets they should also, like release them on the…daily's (newspapers). Those are the things that needs to be on paper, so that our people 'oh ok, this is about disability, these are services, this is how we will access it'" (parent from POM group).

> "Use the media to do all this… just telling everyone that you need an assistive device this is the place where you can come in to get an assistive device and now contact details of the location…would be a better way of doing this. So people are aware. The media information goes down right to the little areas. Then in the village they do it via the radio" (female POM participant).

> "If we have to get information out, it would be nice to use all forms of the media. Whether it be, be TV or through the radio – because some areas don't access TV, and also the mobile networks. Because, if you go anywhere in Papua New Guinea – at least to the most remotest area, someone has a mobile phone. They may not have TV, they may not have radios, but they have access to a mobile phone. So if we had to use awareness, through the media, we consider what is available to the rural areas as well" (parent from POM group).

Awareness campaigns should make use of the community word of mouth communication network: 'Word of mouth' was the most common method that participants in the Questionnaire found out about services. Participants in the focus groups also emphasised that by giving the information to the community through service provider or disabled persons organisations was an effective way of ensuring that more community members would be given the information. The 'word of mouth' network would provide information to a wider audience of people.

> "you must get people like, awareness group must be there to go and do awareness. So people, you know…what's going on, what's happening" (male Alotau participant).

> "And another thing that I believe should be done is that the government through health department should conduct a lot of seminars and help a whole lot, a lot of problems - just like this (focus group)…in terms of disseminating info, disseminating information right to the, to the people that are mostly affected, especially those in the rural areas. They, they cannot access information. But the government must make it's business to go down and conduct awareness to those who are providing, on print, yeah printed materials" (parent from POM group).

Printed materials are an important method of awareness raising and sharing information: Information in brochure or poster format ensures it can travel to remote locations.

> "I believe the health department, the government through the health department, should print out, you know, information booklets, brochures and leaflets so that this information can be spread, even through the, the rural areas. So people have something to, to, to, to read themselves and to know about the services that are available" (parent from POM group).

> "When we are doing awareness in the communities, also give the pamphlets out. So they'll be aware, they'll read them" (male Alotau participant).

"… those informations should be conducted in the language we speak as of today. 'Cos in rural areas, they speak Motu-Pidgin, and Motu. So those information should be sent out to these rural health centres, where public health information would be relayed to all their communities. And, ah, also these elderly people he talk about, we should also make that information available" (parent from POM group).

Include people with a disability and their families in awareness raising activities: In order to strengthen the message and provide positive role models for others in the community, people with a disability and their families should be involved in awareness raising activities.

"I've done a bit of community awareness before…I've gone out to districts in rural places and I think what really works is that people with disabilities … stand out in front in public and we do awareness it's when we tend to empower those back in the village to come out…So I think that's what really worked was people with disabilities themselves doing the awareness" (female POM participant).

"… we ourselves should organise a committee, because we have got this disabilities [people with disabilities] living with us and by experience we should go out and do awareness, telling other people that we have these children at home too, and this is how we take care of them. Besides…the television as we have said, we cannot use other people that don't have these disabilities with them because they don't have the experience. But people with experience will know how to go about it" (parent from POM group).

Awareness raising activities should focus on the rights and value of people with a disability: Changing perception about the role that people with a disability can play in their families and communities will assist to break down attitudinal barriers.

"Another thing – the perception of the, the general public, people in the communities, how do they view – in terms of, respect and honour of people, like, with disabilities? What's the rationale against such people? Awareness should be conducted heavily on that, because, you know, we've, we've got people in various communities who don't have, ah, they've the same love, whereas a mother has for a disabled child, they don't have that. You have our children going to school, someone may have a bad comment on, on one with a disability, or, those can be some of the help that we, we can get from the general public so that person with a disability can be encouraged to move forward in life. And do what he can do as a normal, able person" (parent from POM group).

"So what I suggest here, we should have this going around the rural areas to make clear to the people's minds that this type of people should be assisted or taken care of. We should take care of them. They are just like we normal human beings" (female Alotau participant).

"Because, you know, a lot of people in the communities, or in areas they, they, they, they ah disregard the people with disabilities. They think oh they're…. unproductive, they're useless – you know? But, ah – that, that is another side of the coin, that we, we, we can produce something. I mean, if, if only, you know, there is people that can get us organised, and give us the resources that we need so that we can be, you know, we can be, we, we, we, we can be go, go productive in, I mean in the community with what we are doing, so I mean it's good that we, we come, things are like this that we can, you know, things that you, you, you forgot for us can challenge us, so that we can, we can, we can always cooperate with the community, or work together with them" (male Alotau participant).

14.2   Location

Due to the large number of rural and remote communities in PNG, the location of the major service providers in the towns and cities reduces access.

> "For my mother in law sick she comes from a very remote area where they stay. The hospital is far and it's a distance to get to go for help. There's a lot of people there. Disabled. They're just left like that" (female Alotau participant).

> "How can I get down there? I'm in the bush and I cannot. You know to walk down to the beach is another distance and the dinghy. And no money." (female Alotau participant)

> "… you say the services are here but they can't get the services because what they wanted us is to bring them to the hospital. How can we bring them to the hospital?" (male Alotau participant)

14.3   Socio-cultural beliefs and attitudes

Other people's perceptions and beliefs, relating to gender, age, and culture, directly impact on a person with a mobility disability access to a mobility device and service. Without family or community support, the likelihood of a person being able to access an appropriate mobility device is reduced.

Discrimination of people with a mobility disability is a barrier to community participation and access to mobility device service provision.

> "But what about people with disabilities? And they are many people who, who are with disabilities in the house but when you are willing to show them, and if you talk to them to come and join people with disabilities well they would say no, they will say no I am alright, I not disabled. It's because they are shy to show themselves out. Because there is no recognition of them" (male POM participant).

> "In Papua New Guinea we have a culture where…disabled people are not really recognised. Just like women are not recognised. So I mean, leadership positions, roles in whether in national government, provincial or local level government there's, like, there are some people, like, prominent people who in the community, you know, they will put like first priority if they contest against me, I mean if like a person like me contesting an election, they will put me aside and then they will look at some prominent people in the community who are standing" (male POM participant).

> "… not everyone cares for, for people with special needs. Some of them are neglected, and it's simply because, in their area, you know, life is very hard. They are not able to access these things, so they give up. And they just forget, they neglect people with disabilities" (parent from POM group).

> "… the main thing is ignorance. There are plenty in the village, in the remote areas, especially on the islands. They are just neglected. And they need services. The community, they don't look upon these people. They just ignore them. They laugh at them. Like it's a sad thing to the parents. Sometimes they ask for assistance and the community just talk back to them. And tell them 'that's your burden, it's not for the whole community'" (parent from Alotau group).

Misinformation about the cause of disability can reduce the support provided to people with a disability and their families.

> "….people with a disabilities we tend to be looked upon as the, the cursed ones. That's why we don't get any attention. And a lot of people, and ah, I mean, a lot of us die from lack of attention" (male Alotau participant).

> "I've got a daughter there, she's, she cannot walk. And they say it's a curse. You know, and then we don't get attention" (male Alotau participant).

> "… in your culture it is a form of deformation, deformation of the body …in Papua New Guinea…, it's [a] curse" (male Alotau participant).

Children with a mobility disability can experience violence and neglect from family and community members.

> "…speaking about kids in the village … there are a lot who are neglected, abused because their parents have full time working in the garden, not like in town. They are left there, they even toilet on themselves, they are not cleaned for days sometimes" (parent from Alotau group).

> "She was born like that, when she had a disability. But she was nine months old when the father, the own father told the mother to kill her. 'Why, why you keeping her alive when she has the disability? Can you kill her?' He said, he said, telling her that 'now because we have this child in the family that is, she has a disability we kill her because she is spoiling, stopping us to do our work. And giving us burden.' … But he kept on telling her to 'murder her, to finish her off'" (parent from Alotau group).

Lack of family support is a barrier for people with a mobility disability: Those people with a mobility disability who do not have the support of their family find it much harder to access services and participate in the community.

> "The husband left her when he saw that she was amputated and considered her as handicapped…" (female POM participant).

> "… people are ignorant. Sometimes we tell them, even our relatives, we tell them to help us, but they don't give us their time, what we need from them" (parent from Alotau group).

The 'burden of care' can make it difficult for people to assist their family members the way they would like to.

> "I'm a doctor by profession…. but I left and I had to go and work outside because I had to take care of my daughter's needs. Everything that I, that I had to do, because working in the government organization doesn't give you enough care time for a child with special needs. My daughter has global disabilities so she has the inability to talk, feed herself as well as walk" (parent from POM group).

> "I have a little girl. She was about two years. The grandmother start looking after her. The grandmother passed away when she was about five years. My wife decided to quit job and look after baby" (parent from POM group).

> "… me and my wife, our wear and tear is so fast, you know, 'cos my little girl is so big now. And, looks as if though, like, we're not going to reach even 70. Just 'cos my little girl is so big, you know? … Mama left job, I left job – and who are the breadwinners in the family? Right now we

are losers in the family, we've been begging around – just because of my, my child" (parent from POM group).

"And to take care for the disabled people it's very, very hard, it's not an easy task because when I wake up in the morning I'm their hands, their feet. So I do everything myself" (female participant, Alotau).

Gender related discrimination and violence is a barrier for women with a mobility disability:

"She becomes the, more like a slave … in that kind of society, like when you look at it, the woman is classed as number 2. So the man is like… the master. He becomes the master and then even though you're disabled or not, still you are classed as third, so you become the slave in the house. You do everything. You do everything. That's woman's job. So the woman takes up all the responsibility whether you're able or disable" (female Alotau participant).

"But not all the time. Sometimes the men ...Our men, our men are like I said they're the masters. They can be, they can be so mean. Sometimes they make you hurt. You know, they have that negativity" (female Alotau participant).

People with a mobility disability can contribute to their families and communities: Given the right support, services and assistive devices.

"I have my right to move around to come out of the house… And maybe knowing my rights was the biggest thing. That we have a right to, to be treated properly" (male POM participant).

"…we must not forget that these people can make a contribution to society. They are considered assets for, for the future, in terms of, given the right interventions at the right, appropriate time in their time of need, so that you can cater for that disability. You make this person improve in their life and later on they can make a big contribution to society. So they are not just liabilities for the government, saying that they are useless and this and that. If we give them the, if they are given the right interventions in the right time in their life as they're going, you, you give them skills and give them, you open doors for them" (parent from POM group).

14.4   Service provision

Access to appropriate mobility device service provision is valued by people with a mobility disability.

"…we need the service – but we need the right type of service." (male POM participant)

"In the past they just bring this wheelchair like one size fits all, things like that. And they just distribute it to people whether people like it or not, whether it fits them or not. They just distribute. So we, we had some problems for people like us, paraplegics, and quadriplegics, we can easily develop pressure sores and things from using these things which are not really meant, made, specifically made for us" (male POM participant).

"But we have special people who are the elderlies. Some cannot move themselves, these people need these services, wheelchairs. We have a lot of them out in the rural areas, villages, so these, these services are also meant for them" (parent from POM group).

Local community access to services is essential: Access to mobility device service through community based rehabilitation workers, outreach from centre based services or another model of community service is viewed by participants as a solution to the barriers of transportation and finance.

"… they really need the services to be taken to their villages because for them to travel all the way here to [Alotau]... that's the other side which is 120km dinghy travel then to walk from the

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mountain down to the beach is about two to three days walking down and then get the boat to [Alotau] ... and then get the PMV to come into town. So he said it's very difficult. If only they get the services come to the village and give the people." (male Alotau participant)

"… it's ok I can come, for me to come and go up to service help but I'm talking about the other family, my friends that they're in the village how can they come? It's better you bring the services to us." (male Alotau participant)

"Because some of us we live in the mountain in the bush and others live over the sea and those who come from... therefore what I strongly suggest is training should be given to these people in the rural areas" (male POM participant).

Changing eligibility criteria of some charity and church based service providers can confuse people about their right of access.

"And the way things are being done too is like, people are giving small things here and there so it has to be like one, one system of delivering these services, so that people are not confused" (male POM participant).

"Because at the moment, like I said, people are getting assistances like, people are going and delivering the services to a certain group of people and then another group, another organization group, like this, people see this organization, different types of organizations coming in. There's no one, there's no one general channel or system of delivery. That's the current problem we are having right now" (male POM participant).

"So we have to look for ways to, to establish a form, like a network where, like any other organization who want to come and provide services to assistive devices, services to the communities has to follow the same channel. … It's very, very confusing. So that's just what I wanted to say about the system of delivery and communication networks. It's all over the place at the moment" (male POM participant)

the ****[10] people at ****, they put up an ad, saying that the government had bought you know, some things to assist the people with disabilities – so I, I got my son there, and there were many, many people, relatives brought their children and relatives who were affected. So we were there and then they said 'oh, no this is just for a special group of people'…when they turned my son away that time, I felt that my son was marginalised" (parent from POM)

Lack of support from service providers and government is a barrier to accessing services.

"… many people they come to general hospital and they sit, and people get [a prosthetic] leg, or something when they, they need, crutches or …they [mobility device service] say 'you go buy'…They go and see it, the price is too much for them…so they go home" (female POM participant).

"There is no one else we can rely on because if our own government has overlooked us, who is there that we can turn to?" (parent from POM group).

"Rabaraba is a very big area we are mountain and coast. And people like this, this type of people, disability people, like health workers they don't try to help them to give them this kind of things to support them to walk, or bring them down to the big health centres" (male Alotau participant).

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[10] Personal identifying information removed

"… we need the physios to move around. They may say there's not enough staff to do that. … [but we need] the physios to move around so that they can be able to assist those that are needing help" (female Alotau participant).

"At times, they tell us that we must bring the disableds for them to prove that they are disabled… I cannot be able to carry my, my big niece to get her on the boat and, and to bring her here… See it's so hard for and for a woman for me to come and carry the wheelchair down to the boat and load it on the boat" (female Alotau participant).

Corruption and fraud reduces the confidence of people with a mobility disability in the government system.

"… we saw an ad through the Post Courier. One of the dailies, Post Courier. They put out information, whoever needed wheelchairs… we were desperate, we needed a wheelchair for our son and so they sent, we sent word and we wrote and we paid for it. 50Kina. And it's been three years now and nothing is coming…" (parent from POM group).

"… there is bribery in everywhere, where if you give some money to the doctor or whoever, then they will attend to you. But every time he went to the hospital they would say 'oh come back next week,' and then the next time he goes, 'come back next week' or 'next month.' And he's been facing that problem ever since almost five years now. So it's, if you give money, they will attend to your kids. Ok, it will be a fast process" (parent from POM group).

"… just going towards the end of last year… they put up an ad, saying that the government had bought you know, some things to assist the people with disabilities – so I, I got my son there, and there were many, many people. Relatives brought their children and relatives who were affected. So we were there and then they said 'oh, no this is just for a special group of people'… And so, like, when they turned my son away that time, I felt that my son was marginalised" (parent from POM group).

"Sometimes others recognise us, [service name removed] sometimes take us in there to show the world they're helping but they get money and don't give us. Sometimes my heart is broken" (parent from Alotau group).

Government responsibility for services and support for people with a disability and their families: The PNG government is the right institution to take a lead role in wheelchair service provision.

"...At the end of the day the government has to take charge of these things so really push along that lines" (male POM participant).

 "So I want the government to take the lead in providing these devices and then, like overseas donors can come in and support the government. But at the moment it's opposite" (male POM participant).

"I think that the government are the right people to take ownership of this in the country, in the country. They have the financial resources and all these things that they can, they can, they can take a more proactive role in, you know, looking at disability rights, rights for disability issues, and addressing them and providing the services to where they need, it is needed at the national level and down to the local, provincial and local level government. So, to make it short the government should take ownership. They have the funding's already to take everything, to deliver the services too" (male POM participant).

"… take it to the government and let them know so their first priority must go to the rural ones. You are improving the urban ones and what about the rural ones? Where people are starving there. They don't receive this services" (parent from Alotau group).

Role of disabled person's organisations is to advocate on behalf of people with a mobility disability to government and service providers.

"I think that one thing also I have in mind is that we as the disabled as an organisation…we need to consult and advocate also for the government, for the government to know exactly, to know exactly what type of service that we want" (male POM participant).

"Well what we need to do as disabled persons ourselves is to actually get in touch with these people in the government system that are providing that service, get to those points and tell them you know, and work with them and plan with them and tell them 'ok this is also what we as disabled people want. We need these devices also, we need to service this, rehabilitation, all this different stuff that we need'…we have to get ourselves a part of the plan that is being done by the government system… Sustainability wise government man has to take this on board, take responsibility for these things. So we don't wait in isolation now we have to be seen to be part of the system of government" (male POM participant).

"ADP has been much help to us too. We used go there, and they take us for conference to all these big places, and we see all the people they come and do the, the disabled people they come in with all their things. And, it's, we are a small group in here, but me and my daughter when we go out I see loads of people coming in with these things. They talk about bigger issues, like shopping, like buses, now we are talking about all these things – they talk about it" (parent from POM group).

NOPS is a valued service provider.

"And she's [NOPS staff member] actually vital for all the people in Papua New Guinea who are disabled. And NOPS can assist them. And if only NOPS can extend this service to other centres, like Lae and Rabaul and provincial centres and so the health department, the organizations can just know. Because they are doing a marvellous job" (parent from POM group).

"NOPS can assist in making wheelchairs. Sort of give our kids the privilege and the opportunity in life, particularly in life for them. Like my son, when something is ... he can't move...but because of my, his wheelchair, we can take him away" (parent from POM group).

"NOPS is a very good place. And they started to make Z's leg. At the time when they finished everything off and then put, Z to put on her new leg to going for training and walking. She started to walk. And we were all in tears. So this is really wonderful but what the, the, the thing is, people in Papua New Guinea, they want to know all about NOPS. They need to put this, place to come up to. Everybody should know. That's the place for them, for people like, people who have their legs, arms, anything. So I'm really thankful for a place called NOPS... " (parent from POM group).

Mobility devices lead to independence and visibility.

> "So I'm in this wheelchair now, and, seeing that I am on the wheelchair now I see that life is just back to like I was normal" (female POM participant).

> "I feel that I am somebody with this [wheelchair]" (female POM participant).

> "He's a bright intelligent young man. But just very recently, NOPS assisted with the, giving him a pair of shoes, so he can manage to go up to the school and back. So we don't need to carry him now" (parent from POM group).

14.5   Prerequisites for accessing a mobility device service.

Regardless of the existence of a mobility device service; a person with a mobility disability must be able to overcome a number of pre-existing barriers in order to access the service. Without support to overcome these barriers the likelihood of someone being able to access a service is limited.

Transport is a key barrier to accessing services: Inaccessible transport, or unaffordable transport options for people with a mobility disability is a key barrier for service. Assisting people with a mobility disability to access affordable transport options is a key facilitator of services.

> "As for us who live in the rural areas, transport is no good in this. It is very, very important because when it is very hard for our, the condition to our disability. It is hard for us to come and to knock and use doors or to get assistance..." (male POM participant).

> "Sometimes she gets very sick but I still have to keep her at home. How can I take her to the hospital? How can I take her on a PMV [public transport]? I never knew how to take her to the hospital because I just couldn't do it my way. I cannot get her on a wheelchair to take her to the truck" (parent from Alotau group).

> "But if you have to be transported that you have to pay certain amounts for the disabled person to be transported. And where do you expect the disabled person to get the moneys to pay for the ambulance? And that really saddens me" (female Alotau participant).

> "It's very hard for them because of the road, so, and also the coastal ones they try to come to Alotau to look for help, or treatment, it's very hard for them because of the transport problem. It's very expensive travelling from our end, coming up to the, to town area. It's very expensive, so people are just, living there, they, they stay live there like they, they, they don't think of getting help from people" (male Alotau participant).

Gender based transport issues: The fear of physical assault is a barrier for women to access services, as it prevents them from accessing public transport. There is also a social-cultural issue of the role of women in the community, and they risk negative community opinion if they travel alone.

> Women are unable to travel on public transport alone due to the potential risk of violence: "In the circumstances today, like you, the women are being harassed. Like a lot of marijuana, a lot of drinking and the women get raped. They are victimized. And that is the scare today. And not only raping and, and things like that, but they get killed" (female Alotau participant).

> "… men they don't allow women to go on their own. You know, they have this suspicious minds there like that. Especially we women don't go out on our own. Especially the marriage ones. You know, we have to go certain people when we are guided. And some men they don't understand…they are suspicious of their wives" (female Alotau participant).

"…if we are going with women only, we have to be very careful how we walk. And one little move and we're running... Sometimes we're lucky we get picked up" (female Alotau participant).

Financial barriers: The cost of accessing a device includes the cost of transport, accommodation, food and lost working time (either earning or caring for the family and community). This can be a barrier for many people with a mobility disability.

"…we find difficulty in coming to the hospitals. Some times to see the physiotherapists. Sometimes I miss out on my appointments, I don't come. The, the, the very factor is that sometimes we don't have the money to come to see the physiotherapists. … Sometimes you don't have that, ah, ah, the finance to get us from point A to point B. That's why sometimes we, we are limits out" (male Alotau participant).

"… they find it hard to come, or money to pay bus fares to come across, no money to pay those things there" (male Alotau participant).

"… this old man there, when I bring him on the ambulance, I pay for the ambulance fee… We pay for the ambulance fee. I mean, ambulance should be taking us free, like for those people, but instead we pay for the ambulance to take us too" (male Alotau participant).

"As mothers, they have children and they have responsibility to make money because they don't work they don't earn anything. So to make money to pay for their children's school fees and especially with women with disability it's very, very difficult for them to provide for their children" (female POM participant).

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