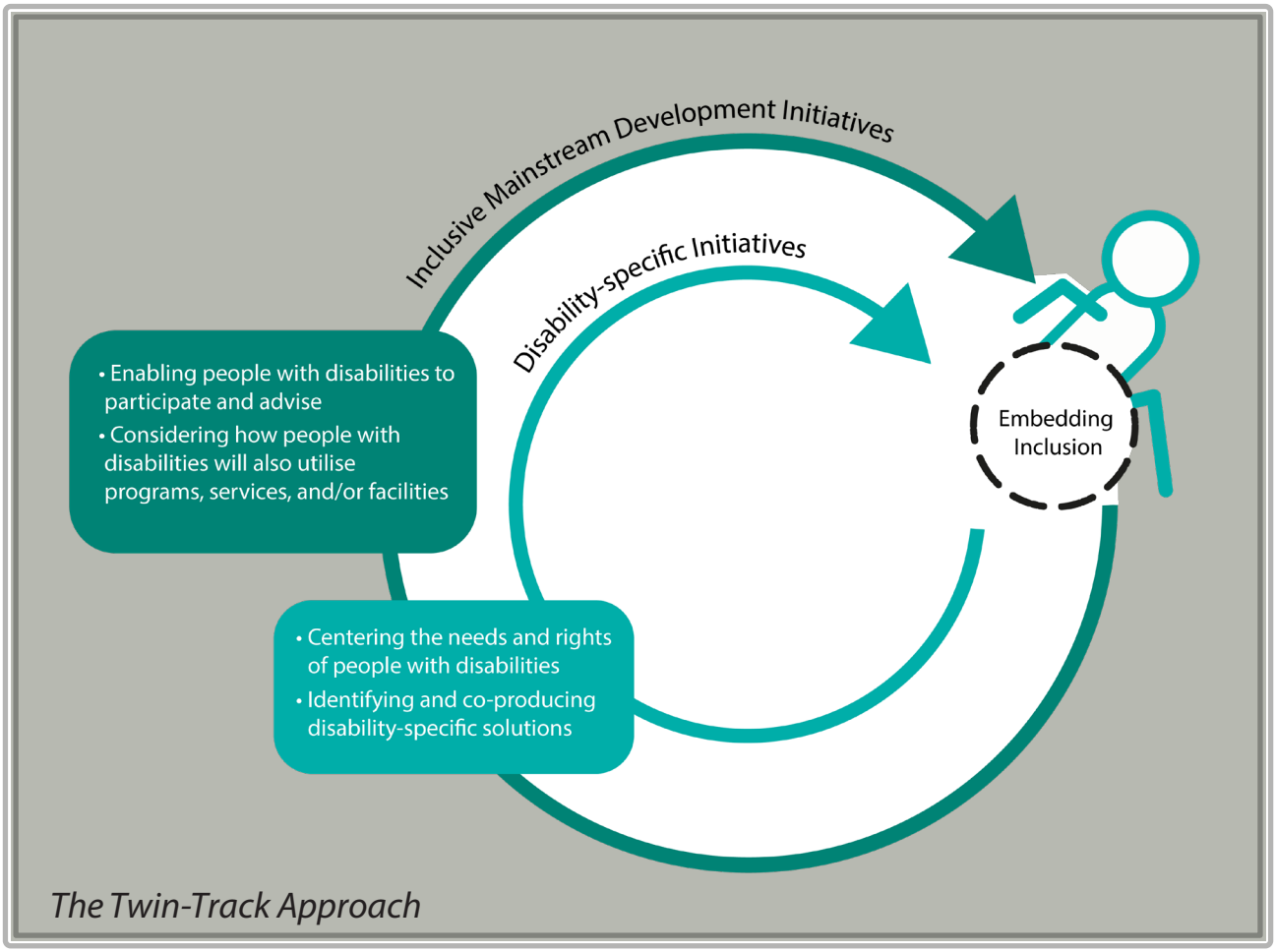
Research for All:

Making Research Inclusive of People with Disabilities



Providing tools and resources for practitioners, researchers and policymakers to ensure best-practice in disability-inclusive development

RESEARCH FOR DEVELOPMENT IMPACT NETWORK

A collaboration between the Australian Council for International Development and Australian universities

THE UNIVERSITY OF MELBOURNE

Melbourne School of Population and Global Health
Nossal Institute for Global Health

cbm

PACIFIC DISABILITY FORUM

Research for All:

Making Research Inclusive of People with Disabilities

The RDI Network acknowledges the Traditional Custodians of the land of which we work, play and live, and pay our respects to Elders past, present and emerging. The RDI Secretariat work on the land of the Kulin Nation.

The report was authored by consultants on the land of the Kulin Nation.

We wish to recognise the ongoing inter-generational trauma suffered by Aboriginal and Torres Strait Islander families and communities as impacted by colonial invasion and control.

The RDI Network values the experience and contribution of people from all cultures, genders, bodies and abilities. We celebrate diversity and respect for all.

About the Research for Development Impact Network

Established in 2009, the Research for Development Impact Network (RDI Network) is a network of practitioners, researchers and evaluators - working in international development. The Network has become a key outlet for accessing diverse research expertise, supporting collaborative partnerships, and encouraging supporting ethical research practice among non-government organisations (NGOs) and academia in Australia. The RDI Network is a partner of the Australian Council for International Development (ACFID). The RDI Network also acknowledges funding support from the Australian Government Department of Foreign Affairs and Trade (DFAT).

For more information about the RDI network, visit https://rdinetwork.org.au/

About CBM Australia

CBM is an international Christian development organisation devoted to improving the lives of people with disabilities in the poorest places on Earth. Poverty and disability go hand in hand in creating a cycle of inequality, isolation and exclusion that leads to the most extreme forms of poverty.

Through its 110-year history and with over 30 years in Australia, it has developed proven community-based programs that help millions of people create real, lasting change. For more information, visit https://www.cbm.org.au/

About the Nossal Institute for Global Health

The Nossal Institute for Global Health Limited works on practical solutions to pressing global concerns. It combines real-world experience with the scientific rigour of one of the world's top universities, the University of Melbourne. Its big picture perspective helps it to understand complexity and change, and to integrate that understanding into country and regional strategies. Its work benefits from the flexibility and responsiveness of the Institute's not-for-profit company.

About the Pacific Disability Forum

The Pacific Disability Forum (PDF) is a regional peak body that works in partnership with Disabled Persons Organisations (DPOs) in the Pacific region. Its aim is to build the capacity of these organisations and improve the lives of persons with disabilities in the Pacific through advocacy. Since its formation in 2004, PDF has worked hard to advocate for disability issues in the region and internationally.

About the research team

This guidance was developed in partnership with the RDI Network, CBM Australia and Nossal Institute for Global Health. Thank you to who those who have provided significant support and input into this guide, particularly:

- **RDI Network Steering Group members:** Leanne Dowse (The University of New South Wales), Helen Fernandes (TEAR Australia), Nazanin Zadeh-Cummings (Deakin University), Ben Clare (Independent Consultant), Gareth Beyers (Plan International Australia).
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Executive Summary

Developing programs to be inclusive of people with disabilities ensures that **all** people benefit. Acknowledging and understanding the lived experiences of people with disabilities is essential in changing the paradigm that development programs 'do to' or 'do for' a specific vulnerable and marginalised portion of the community. It addresses issues of equity and of development effectiveness.

In every society there are people that experience some form of disability. In fact, it is estimated that 15 percent of the world's population lives with a disability; the majority of whom live in low and middle-income countries (LMICs) (World Health Organisation [WHO] & World Bank Group [World Bank], 2011). Therefore, each stage of planning, implementing, and evaluating of development programs needs to consider how to best accommodate and include people with disabilities, whether the project is specifically about disability or not. This includes any research or evaluation carried out with human participants. Increasing the participation of people with disabilities in developing and evaluating programs ensures self-agency, self-determination and allows for effective, sustainable development outcomes.

This guidance provides tools and resources for practitioners, researchers and policymakers for **any and all forms of research, or evaluation with human participants**, to ensure best-practice. This guide is for ensuring that all people with disabilities within the population or community are not excluded (either purposefully or accidentally, through poor planning or inexperience) in doing development research or evaluation. The guide is not specifically designed for those doing research or projects solely focusing on people with disabilities.

This guide is divided into three sections for addressing and implementing good practice in development research.

A summary of the sections is provided (**pages 6-7**).

Section One: Principles and Assumptions

Section Two: Ethical processes and informed consent in research

Section Three: Practice Across the Research Cycle

Section One sets out the fundamental principles and ethical considerations of disability-inclusive development (DID) research. This includes an overview of the rights-based approach to disability, and its guidance in shaping development. This section covers:

- The contextual background for perceptions of disability in low-and-middle income countries (LMICs).
- Common misconceptions and assumptions about people with disabilities.
- The key role of Disabled People's Organisations (DPOs) within development.
- Discussions and advice on supporting ethical partnerships for research.

Section Two discusses the ethical considerations for designing inclusive research questions and methods, including when working with children with disabilities. This involves enabling and obtaining informed consent.

Whilst it is not possible for this guide to cover all scenarios, potential examples are highlighted. Key processes and considerations described include:

- Gaining ethics approvals to work with people with disabilities.
- Providing information about the research process, research tools, and research reports, in ways and in formats that are accessible to people with different types of impairments.
- Enabling 'informed consent' by providing potential participants with necessary *and* accessible information. This includes facilitating genuine and informed decisions about how they want to participate in the research.
- Ensuring the right to privacy for participants and confidentiality of information.
- Providing appropriate support structures to manage the potential effects of involvement for people with disabilities and other members of the research team (e.g. providing feedback, debrief and complaint pathways that are realistic, safe, and accessible).

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Section Three details the key steps and processes for ethically involving people with disabilities throughout the four main phases of the research process: planning, design, implementation, and dissemination.

Refer to different parts of this section during planning and implementation of research projects to ensure that the practice is inclusive. See **Appendix 1** for a research cycle checklist to use.

- **Planning Phase:** develop meaningful research partnerships, understand the definition of disability, build team capacity for working with people with disabilities, and budget for inclusive research and reasonable accommodation.
- **Design Phase:** develop disability-inclusive research questions, as well as identify ethical and inclusive methodologies to including people with disabilities as co-researchers, team members and participants.
- **Implementation Phase:** outlines strategies for promoting inclusion within data collection and analysis, and capacity building activities.
- **Dissemination phase:** outlines approaches to ensure research findings and forums are accessible to people with disabilities. This includes acknowledging their lived experience, contributions, and labour through the practice of co-authorship.

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Acronyms

ACFID	Australian Council for International Development
CRPD	Convention on the Rights of Persons with Disabilities
DFAT	Department of Foreign Affairs and Trade
DID	Disability-inclusive Development
DID4All	Disability-inclusive Development for All
DPO	Disabled People's Organisation
IDA	International Disability Alliance
LMICs	Lower-and-Middle Income Countries
NGO	Non-Governmental Organisation
NHMRC	National Health and Medical Research Council
OPD	Organisation of Persons with Disabilities
RAD	Rapid Assessment of Disability
RDI Network	Research for Development Impact Network
SRH	Sexual and Reproductive Health
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations Children's Fund
WASH	Water, Sanitation and Hygiene
W-DARE	Women with Disability Taking Action on Reproductive and Sexual Health (Research Project)
WGSS	Washington Group Short Set of Questions
WHO	World Health Organisation

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Glossary of Terms

Ableism

Ableism is a term to describe the discrimination that people with disabilities experience. This form of discrimination includes being excluded from decision-making and autonomy, being denied access to information and physical spaces due to language barriers and poor planning, as well as having less rights recognised than people without disabilities. This form of discrimination comes from an underlying and false belief that people with disabilities are, by default, inferior, 'less than' or helpless.

Barriers

Barriers are defined as attitudinal and/or societal actions, physical and/or environmental factors, and policy and/or systemic issues that create a disabling effect. Examples of barriers can be stigma (social), exclusive use of stairs in buildings (physical/environment), lack of accessible information (communications) and/or lack of funding for a specific type of mobility aid (policy/systemic).

DID4All

DID4All is a website specifically for disability inclusion resources for individuals and organisations working in international development. These resources are developed by CBM Australia, the Nossal Institute for Global Health, University of Melbourne and other disability stakeholders. The website is funded by the Australian Government. Please visit https://www.did4all.com.au/

Disability-inclusive Development (DID)

Disability-inclusive Development promotes equitable and effective development by recognising that, like all members of a population, people with disabilities are both beneficiaries and agents of development. DID seeks to redress systems and processes which prevent people with disabilities from participating in, and benefiting from, development.

The **explicit** inclusion of people with disabilities as active participants in development processes leads to broader benefits for families and communities, reduces the impacts of poverty, and positively contributes to a country's economic growth.

Disability-inclusive Research

Disability-inclusive research seeks to reveal and address the inequities experienced by people with disabilities. Such research seeks to improve the effectiveness of development practice by including and centering the voices, needs and priorities of people with disabilities in research efforts and actions.

Disability-inclusive research aims to ensure people with disabilities have the **same opportunities** as individuals without disabilities to contribute to, participate in, and benefit from development research.

Disabled People's Organisations (DPOs)

Disabled People's Organisations (DPOs) are organisations made up of persons with disabilities and which exist to represent the interests of their members. Increasingly DPOs are using the term OPD (Organisations of Persons with Disabilities) to refer to themselves. Although there is no firm rule, best practice is that DPOs comprise a voting membership of people with disabilities, and a board, of which at least a majority (usually 51% or over) is made up of people with disabilities. Some DPOs represent people with all impairment types, while others may focus on a particular impairment type, gender, sectoral issue, or represent geographical areas (local, provincial, national, regional or international).

Evaluation

Evaluation is a type of applied research commonly undertaken for the "systematic, objective assessment of an ongoing or completed project, program or policy" ("DAC Glossary," 2020). Evaluations in the development sector are routinely used to assess and improve the quality and effectiveness of development approaches and activities.

Impairment

A characteristic or condition that contributes to difficulty in functioning. This can include difficulty walking, seeing, learning or increased sensitivity to stimulus.

Informed consent

Informed consent is where an individual freely gives permission to participate in an activity or action. The individual giving permission genuinely understands the benefits, risks, and consequences of participating. The individual is not pressured, coerced, or forced into giving permission.

Othering

Othering is the act of viewing and/or treating (intended or unintended) a proportion of the population or community as intrinsically different from and alien to oneself. In the context of working with people with disabilities, this may look like not realising that people with disabilities have dreams, hopes and ambitions of their own, or *only* inviting people with disabilities to participate in disability-specific projects, as opposed to ensuring all projects are inclusive.

Participatory action research

A research approach that emphasises local participation and action. It is commonly used to enact self-determined improvements in living conditions and practices for a range of environments. In relation to disability-inclusion, its focus is on improving the autonomy and agency of people with disabilities by engaging people with disabilities to generate solutions to practical problems. It connects development practitioners to the needs and ideas of people with disabilities in research and the development of implementation activities.

People with disabilities

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) conceptualises people with disabilities as those who have episodic or long-term physical, mental, intellectual or sensory impairments, which, in interaction with other barriers, may hinder their full and effective participation in society on an equal basis with others (United Nations [UN], 2006). Notably, the CRPD conceptualises disability as the interaction of **impairment** and **barriers** which can create a disabling effect.

Plain Language Statements

Documents written in plain, everyday language that avoid using jargon. Plain Language Statements are used to ensure that potential participants of a research project are informed about the process. These Statements provide a clear and succinct description of the project agenda, process, complaints, and feedback channels, as well as any perceived risks.

Positionality

The concept that one's identity, views, opinions, and potential biases are influenced by one's social, cultural, and political contexts, such as race, class, gender, sexuality, disability, education, job and/or family status.

Reasonable Accommodation

Specific support or modifications, requested by a person with a disability, that are required to address a specific barrier to participation. The support or modification enables people with disabilities to enjoy their rights on an equal basis with others. It can also apply to addressing barriers for a person who has a care-giving responsibility for a person with a disability.

Research

Research is "an original investigation undertaken to gain knowledge, understanding and insight" (National Health and Medical Research Council [NHMRC], 2018). It is an inquiry and knowledge-gathering activity that aims to contribute to social, environmental, cultural, or political change, especially in policy and practice (RDI Network, 2020).

Rights-based approach

An approach to policies, practice and programming underpinned by *how* human rights can be achieved for all people.

Twin-track approach

The twin-track approach refers to the need for mainstream development programs to be inclusive of people with disabilities; as well as for initiatives targeting people with disabilities to address specific barriers and accelerate efforts towards disability inclusion. See **Figure 3**.

Using this Guide

This *Research for All* guidance document aims to support development researchers and practitioners to ensure inclusion of people with disabilities throughout research and evaluation undertaken in the development sector. It is expected to be used as a guide for researchers and organisations who may conduct research. This guide can also support DPOs to gain a better understanding of how researchers should be engaging, as to confidently negotiate how people with disabilities can be involved in research processes.

Within this document you will see a few icons to help you navigate different content areas:

Recognise the 'gems' and value-add to disability-inclusive practice.

Look out for and pay attention to these topics to implement better systems and processes for inclusivity.

Beware; these are sensitive issues so tread carefully with your actions and language.

Take practical actions or steps for best-practice in disability-inclusive research.

Ask questions to make decisions for more effective and inclusive research practices.

Establish a milestone in planning for research planning and design.

A Glossary of Terms is at the start of this guide; Further Resources and Reading and References are at the end. At the end of each section, there is also is a list of Key Resources and Further Readings.

Language Guide

Language constantly evolves and changes. Many words used in the past that used to describe people with disabilities are now no longer acceptable ("The Language," n.d.).

Acceptable language to describe people with disabilities vary from country to country, region to region, community to community. It is best to work with individuals, local communities and DPOs to define the most suitable language to use.

Following the language of self-identification of the people that you are working with will be the most appropriate and respectful approach. However, this may not always be possible due to safety reasons and stigma. At the time of writing and in Australia, it is recognised that best-practice is to use people-first language. This means using terms such as:

- A person with a disability, a person with cerebral palsy, a person who experiences seizures
- A wheelchair user, a person who uses mobility aids
- A person who is hard of hearing and/or is non-verbal
- A person without a disability

Introduction and Scope

Globally, about 15 out of every 100 people have a disability, many of whom live in low and middle-income countries (WHO & World Bank, 2011). Yet, historically, people with disabilities have been excluded from humanitarian initiatives and development. One of the factors contributing to this exclusion is the fact that people with disabilities have also been excluded from development *research* and *evaluation*.

However, excluding people with disabilities from development research and evaluation undermines the effectiveness of development programming.

Failure to consider people with disabilities as service users can lead to programs that **1)** fail to address or **2)** compound the socio-economic and health inequities experienced by people with disabilities (Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, 2015).

It is now recognised that knowledge and understanding of the lived experiences of people with disabilities is essential for planning, implementing, and evaluating the effectiveness of development programming (Goujon et al., 2012). This parallels with the recognition that including people with disabilities and partnering with local DPOs throughout research processes also improves research outcomes.

This holds true for projects with a focus on disability, *and* for those with a more general scope. By planning 'from the margins to the centre', considering needs of people with disabilities (and/or any other forms of marginalisation) will improve the relevance, validity and effectiveness of both research and development programming. It can also influence other projects to be more inclusive. Additionally, it helps break down the power differentials that contribute to the ongoing inequities experienced by many people with disabilities (Walmsley & Johnson, 2003; Barton, 2003; Barnes, 2005; Vaughan et al., 2019; Smith-Merry, 2017).

Disability-inclusive research and evaluation (herein now referred to as research for brevity) aims to ensure people with disabilities have the **same opportunity** as people without disabilities to contribute to and benefit from development programming, whilst also building capacity within the disability community to frame research and development agendas.

The ACFID and RDI Network's ***Principles and Guidelines for Ethical Research and Evaluations in Development*** (Principles and Guidelines) (2017) highlights the power imbalances that are intrinsic to conducting research in LMICs. These challenges are amplified when the researchers engage with potentially vulnerable groups, including people with disabilities – who will be present in every community. People with disabilities are often amongst the most marginalised and are often subject to stigma or discrimination.

Research can inadvertently reinforce this marginalisation. When people with disabilities are intentionally or unintentionally excluded from meaningful participation in the research process, there are ethical implications related to justice, and equitable access to the benefits of research. The quality of research is also impacted. If the voices of people with disabilities are not included in research, then the quality of findings and outcomes will be compromised.

"To be effective in reducing poverty, development must actively include and benefit people with disabilities … Research provides opportunities to better understand the challenges and opportunities for people with disabilities in particular country contexts, and improve development practice."

- Department of Foreign Affairs and Trade [DFAT], 2015

Conversely, research that challenges the existing norms around disability can put some groups at risk. Specific impairments such as intellectual or psychosocial impairments can also make some groups more vulnerable to coercion or victimisation. It should be acknowledged that "even when the basic intention of a project is positive (for example to improve the health, nutrition or access to water of a community), change can still have negative consequences." (RDI Network, 2020, p. 9). Ethical considerations in disability-inclusive research will be discussed in **Section Two** of this guide.

It should be acknowledged that there are both benefits and challenges in working towards disability-inclusive development. Many development researchers and practitioners have limited experience working with people with disabilities. This inexperience may cause people without disabilities to resist including people with disabilities due to a myriad of factors; from fear of causing (unintentional) harm or offence to people with disabilities, to being required to personally challenge organisational norms. As such, entry points are specified at the end of each section to guide decisive action, discussion, and reflection for change.

Section One: Background Principles and Assumptions

Summary: This section sets out the fundamental principles and assumptions grounding development research. An overview of the rights-based approach to disability and how this informs disability-inclusive development is then detailed. This is followed by contextual background on disability in low-and-middle-income settings. The key role of Disabled People's Organisations within development is highlighted, alongside a discussion on supporting partnerships for research.

The guidance offered in *Research for All* is grounded in the following principles and assumptions:

- All research must apply universally accepted principles of ethical research. Ethical research refers to the conduct of research under a set of guiding principles and moral values to guarantee respect of persons involved, to protect their rights and to ensure minimal risk for both researchers and participants in the process. Drawing on the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007), the ACFID and RDI Network's *Principles and Guidelines for ethical research and evaluation in development* (2017) outlines the four core values underpinning ethical research:

  I. Respect for human beings is an overarching consideration and represents recognition of each human being's intrinsic value.

  II. Beneficence is action that is done for the benefit of others, the expected benefit to participants or the wider community justifies any risks of harm or discomfort to participants.

  III. Research merit and integrity: research deemed to have merit is well justified, meets relevant quality criteria and is conducted by persons or teams with sufficient experience and competence. Research integrity is secured by research (and the research funder's or commissioner's) commitment to genuine search for knowledge and understanding.

  IV. Justice is generally described in relation to equity: a fair process for recruitment of research participants; no unfair burden of participation on particular groups; and fair distribution of and access to the benefits of participation in research.

- People with disabilities are the central knowledge holders of their lived experiences of disability and have the capacity to contribute this knowledge through research.
- Resourced partnerships with Disabled People's Organisations and people with disabilities form the basis of research, and enable people with disabilities to:

    I. **Help frame** the research and ensure it has tangible benefits for people with disabilities.

    II. **Share ownership** of the research processes and outcomes.

    III. **Negotiate their own participation** in the research as decision-makers, advisors, researchers, trainers, and research participants.

    IV. **Utilise the research findings** to further the interests of people with disabilities and their inclusion in development.

- Research seeks to address the inequities experienced by and improve the lives of people with disabilities by ensuring their voices, needs and priorities are central to efforts and actions to improve the effectiveness of development practice.

What is Disability?

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the guiding international framework for understanding and approaching disability. The CRPD describes people with disabilities as encompassing "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UN, 2006).

It is of key importance to the conceptualisation of disability as set out in the CRPD to understand that disability arises not only from impairment (a characteristic or condition in body functions or structures that hinders mobility, thinking, remembering, seeing and/or hearing), but also from the interaction between a person's **impairment** and the various **barriers** that they experience to reach full participation in their community. See **Figure 1.**

The CRPD also recognises that disability is an evolving concept, and that it has been understood differently by societies over time and across different contexts. People with disabilities are a diverse group. The experience of an individual will vary widely not only according to their impairment, but also due to factors including age, sex, gender identity, ethnicity, class or caste.

This is known as **positionality** (RDI Network, 2020). See **Figure 2**. However, people with disabilities are often amongst the poorest and most marginalised people in any community.

Figure 1: Not all disabilities are visible

There are many different kinds of disability. Some people are born with conditions (such as genetic disorders) that lead to disability and some people acquire conditions (such as through accidents or illness) that lead to disability. Some people may have more than one type of disability. Disability may be visible or hidden, may be permanent or temporary, and may have minimal or substantial impact on a person's abilities.

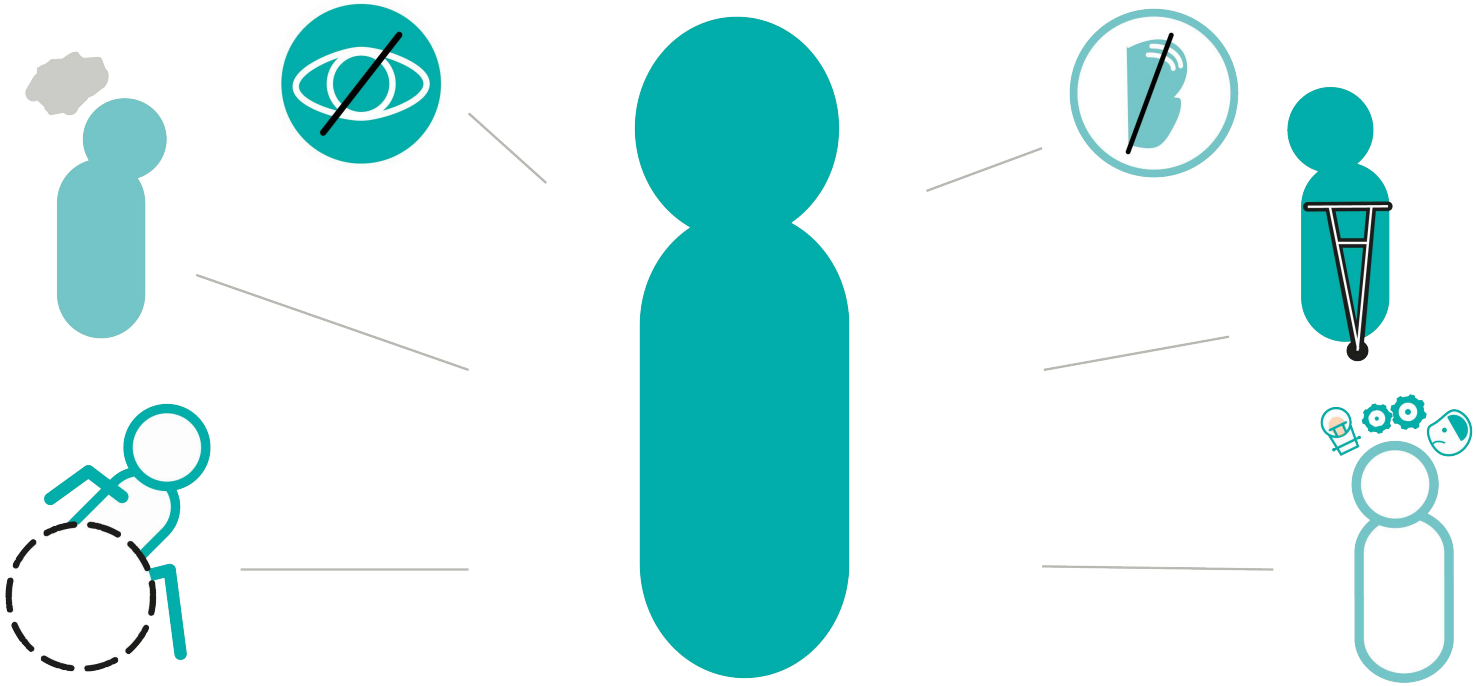
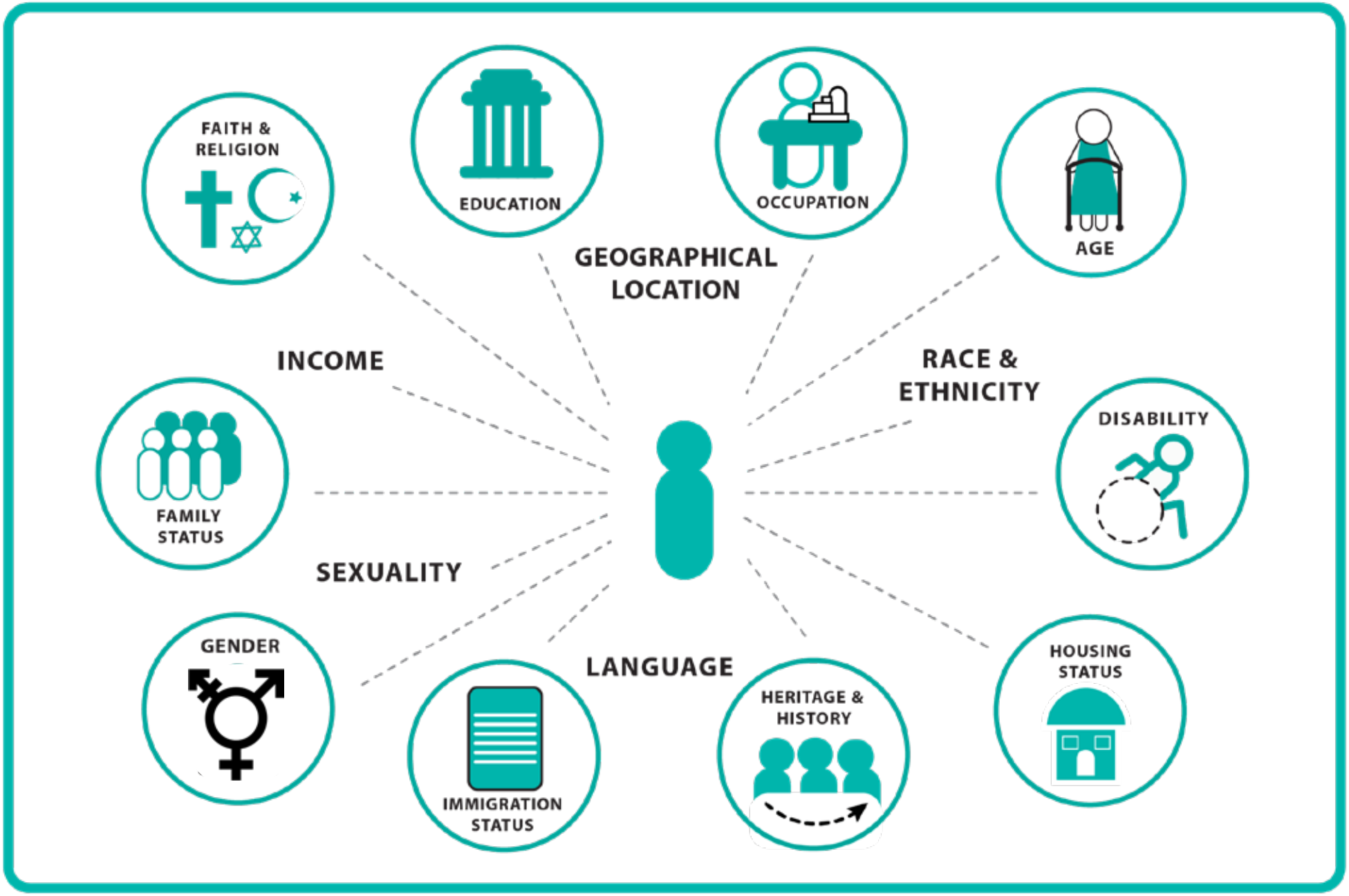


Figure 2: Positionality



Rights-based Approach to Disability

The CRPD takes a rights-based approach to disability. A rights-based model takes universal human rights as a starting-point. It recognises that people with disabilities have the same civil, cultural, economic, political and social rights as all other people, and that they should be able to enjoy all of their rights on an equal basis with others, free from discrimination.

The CRPD itself does not establish any new human rights for people with disabilities. Rather, it clarifies how existing rights apply to people with disabilities, and what the obligations are for States to promote, protect and ensure the rights of people with disabilities. Article 32 of the CRPD on international cooperation states that "international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities" (UN, 2006).

The **rights-based approach** draws on the social model of disability, which focuses on society and the barriers that exist that exclude people with disabilities.

To achieve full inclusion and ensure that people with disabilities can enjoy their rights, there needs to be a shift in society so that these barriers are addressed, accessibility is promoted, and policies and practices are improved. This contrasts with other outdated models of disability, which have been used at various times to understand disability, such as:

- The **charity model** of disability characterises people with disabilities as victims or objects of pity, and as requiring care or support. In this model, disability is often portrayed as a tragedy or source of suffering, instead of recognising that disability is an expected part of human diversity.
- The **medical model** of disability focuses on disability as a health condition, requiring medical intervention or treatment. Although it is important for people with disabilities to have access to health care, focusing only on the medical aspects of disability ignores the fact that many people with disabilities do not want to be 'cured' or 'fixed'. It also ignores that there are social, attitudinal, and physical barriers that exist within our society for people with disabilities that also need to be addressed (DFAT, 2015).

Disability-inclusive development

Disability-inclusive development seeks to ensure that people with disabilities are fully included in development processes as agents and beneficiaries of development programs, on a full and equal basis with others in their communities. The Department of Foreign Affairs and Trade's (DFAT's) *Development for All 2015-2020* Strategy notes that "to be effective in reducing poverty, development must actively include and benefit people with disabilities" (2015).

See **Appendix 2** for strategies to promote the inclusion of people with disabilities in research.

People with disabilities have often been excluded from the agenda setting in development, as well as the processes and outcomes of development programs.

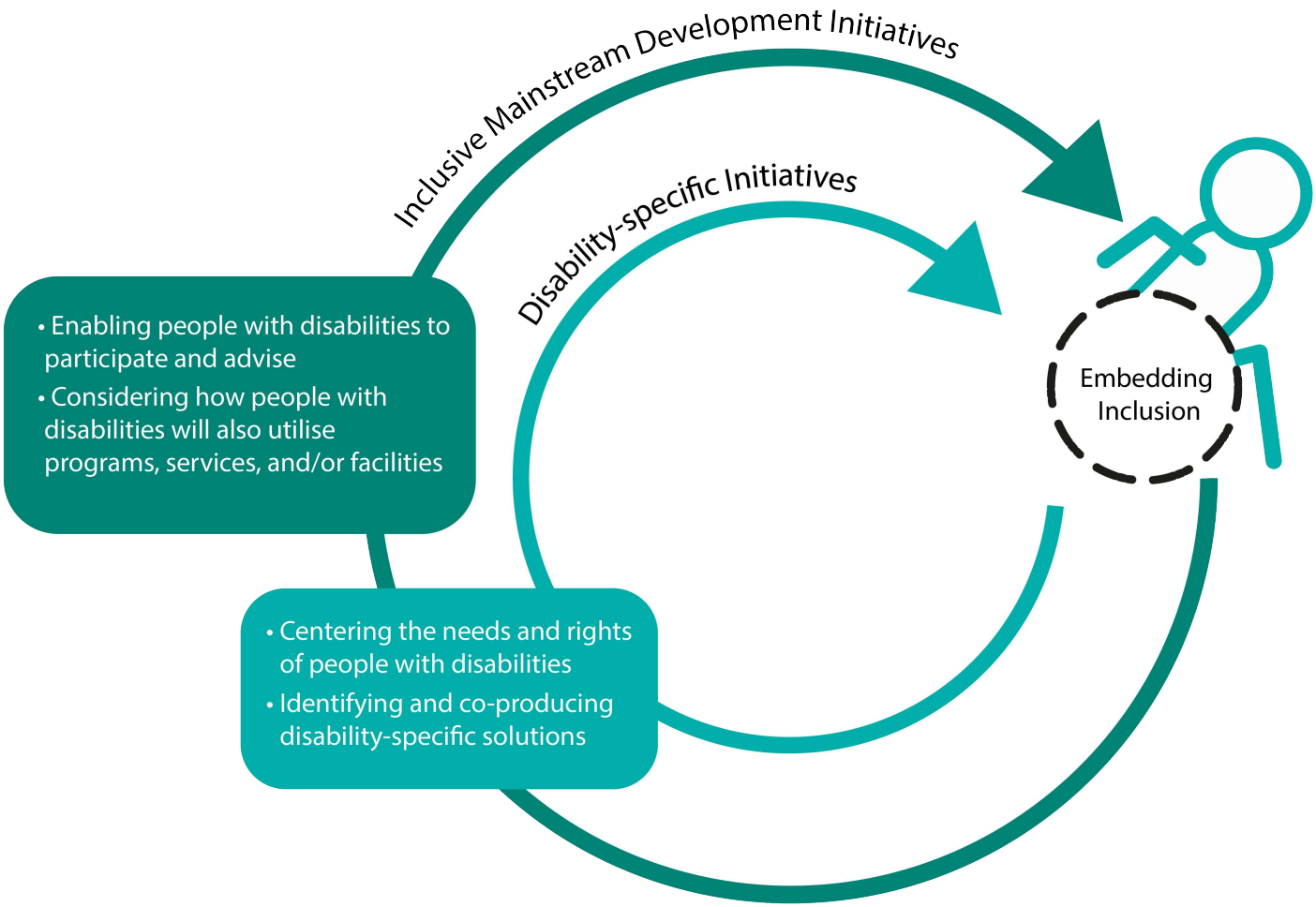
This contributes to the inequities experienced by many people with disabilities in all contexts of development and highlights the need for an explicit focus on disability-inclusion within the development sector. The DID4All strategy outlines the **twin-track approach** to disability inclusion. The twin-track approach refers to the need for mainstream development programs to be inclusive of people with disabilities; as well as for initiatives targeting people with disabilities to address specific barriers and accelerate efforts towards disability inclusion. See **Figure 3.**

Examples of disability-specific initiatives include capacity building for government services to improve provision of assistive devices (such as mobility aids), and support and capacity building for DPOs (DFAT, 2015). Examples of disability mainstreaming include ensuring a Water, Sanitation and Hygiene (WASH) program is inclusive of, and accessible to, people with disabilities.

The twin-track approach can also be applied to research. The DID4All strategy notes that "research provides opportunities to better understand the challenges and opportunities for people with disabilities in particular country contexts, and improve development practices" (DFAT, 2015, p. 9).

In addition to disability-specific research conducted in the development sector, **all research** in this sector should be inclusive of the perspectives and needs of people with disabilities and all barriers to their participation should be removed.

Figure 3: The Twin Track Approach



DFAT has supported the growing body of work in this key area through funding disability-specific and disability-inclusive research such as:

- **The Triple Jeopardy Project**: improving understanding and identifying ways to address abuse and violence experienced by women and girls with disabilities in Cambodia (Astbury & Walji, 2013). See **Case Study A.**
- **The Travelling Together Project:** influencing road transport policy in Papua New Guinea to be more inclusive, by gathering evidence about how people with disabilities are involved in road consultation and planning processes (James et al., 2012). See **Case Study K**.
- **The Costs of Exclusion and Gains of Inclusion Project**: improving understanding of the economic costs of exclusion and gains of inclusion of people with disabilities in low-and-middle-income countries (LMICs) (Morgon Banks & Polack, 2014).
- **The Rapid Assessment of Disability (RAD)**: developing a survey tool to support the collection of disability related data to inform and evaluate disability-inclusive development (Nossal Institute for Global Health and Centre for Eye Research Australia, n.d.).
- **Individual Deprivation Measure (IDM):** developing disability indicators for inclusion in the IDM multidimensional measure of poverty, allowing disaggregation by disability as well as gender ("Individual Deprivation Measure," n.d.).
- **Lived Experience of Psychosocial Disability and Social Inclusion**: a participatory Photo Voice (PV) study in Rural India and Nepal to better understand the experiences of people with psychosocial disability (TEAR Australia, 2017).

Case Study A: Disability-inclusive Development – the Triple Jeopardy project in Cambodia (A summary of *From Evidence to Impact* 2017a: 74-80)

The *Triple Jeopardy* research project aimed to understand the prevalence of gender-based violence (GBV) experienced by Cambodian women with disabilities. The findings were to be compared to their peers without disabilities, and existing policies and programs were to be assessed for inclusion. The secondary aim was to explore the levels of access women with disabilities experienced when engaging with existing programs.

Approaches to Inclusion

Triple Jeopardy included researchers from organisations representing both women's development and people with disabilities. From Australia, there was International Women's Development Agency (IWDA) and CBM Australia. From Cambodia, there was the Cambodian Disabled People's Organisation (CDPO) and the women's organisation, Banteay Srei.

Bringing together key stakeholders from the different policy and organisational sectors of gender and disability assisted in an inclusive research design. It also allowed for outcomes that bridged organisational and policy 'silos', where organisations feel able to work together and share knowledge. Significantly, the working paper also has an Acknowledgments section that thanks all those who contributed to the research project, including the research participants—the women who shared their experiences of gender-based violence and disability to ensure a collaborative, not extractive, approach.

Tools and Methodology

A participatory approach to the research design and implementation ensured joint learning about the different encounters of women with disabilities experiencing violence and their access to support services. It ensured that expertise was available in all areas, including research, disability, and gender, and that each partner learned new skills from the others, developing mutual capacity.

The *Triple Jeopardy* project demonstrated the principle of 'nothing about us without us' by including women with disabilities as researchers. The project provided significant research training and capacity strengthening of local partners in the process. This ensured that there was ongoing involvement of team members and research beneficiaries in the research, as well as in the advocacy and implementation of the research findings.

Learnings

Working with local partners built trust and mutual understanding. This facilitated the co-production of a working paper and high-quality training resources in English and Khmer. The targeted training tools for community organisations also led to an increased emphasis on gender equity in DPOs because of the involvement of women with disabilities on the research team. The women involved in developing the tools were able to bring their knowledge to advocate for gender equity in their own organisations.

The project is highly regarded nationally and internationally and was awarded in 2009 for its work in centering the experiences of women with disabilities living with gender-based violence. It is commended that the project took appropriate advantage of windows of opportunity in policy and strategy development to contribute to the inclusion of the specific needs of women with disabilities.

Figure 4: Phon Chhoun and her children. Participant in a disability-inclusive project in Cambodia.

Image supplied by © Lisa Fitzgerald 2017

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Key Resources and Further Reading:

- **Appendix 2:** Fact Sheet B from the W-DARE guidelines outlines inclusive principles and strategies to promote inclusion of people with disabilities in research
- CBM. (2012). *Inclusion Made Easy: A Quick Program Guide to Disability in Development*. CBM-Nossal Partnership for Disability-Inclusive Development. Retrieved 14 April 2020, from https://www.cbm.org/fileadmin/user_upload/Publications/cbm_inclusion_made_easy_a_quick_guide_to_disability_in_development.pdf
- ListenABLE. (2020). *Challenge what you think it's like to live with a disability*. ListenABLE [Podcast]. Retrieved 8 April 2020, from https://www.podcastoneaustralia.com.au/podcasts/listenable
- People with Disability Australia. *History of Disability Rights Movement in Australia – People with Disability Australia*. People with Disability Australia. Retrieved 8 April 2020, from https://pwd.org.au/about-us/our-history/history-of-disability-rights-movement-in-australia/

Context for people with disabilities in low-and-middle income countries

In many contexts, people with disabilities experience exclusion across numerous life domains, which can lead to a cycle of disability and poverty. The 'cycle of poverty and disability' refers to the fact that people with disabilities are more likely to be poor, while those living in poverty are more likely to acquire a disability. One in five of the world's poorest people has a disability (WHO & World Bank, 2011).

Disability can lead to poverty, due to social and structural factors such as a lack of access to education and lower levels of employment, which then leads to a reduced income (Groce et al., 2011).

Disability can also affect household incomes due to increased caring responsibilities for family members of people with disabilities (Morgon Banks & Polack, 2014, p. 33). People with disabilities regularly face increased costs for health care and extra costs for rehabilitation, assistive devices, support services and transport.

In turn, living in poverty increases the risk of people acquiring a disability. Malnutrition can impair development; poor health care can mean inadequate treatment for disease and injury; poor work conditions increase the risk of injury; and living on marginal lands means that those living in poverty or on low incomes are more likely to be impacted by disasters.

Other forms of disadvantage that contribute to the 'cycle of poverty and disability' include:

- People with disabilities are often excluded from **education**, in particular formal education, with children and youth with disabilities less likely to start school or attend school than other children. Lack of education has a significant impact on poverty in adulthood (Morgon Banks & Polack, 2014, p. 33).
- People with disabilities are less likely to be **employed** than people without disabilities (Morgon Banks & Polack, 2014, p. 33). If they are employed, they often earn less, and women with disabilities commonly earn less than men with disabilities (Morgon Banks & Polack, 2014, p. 36).
- People with disabilities have more difficulty accessing **health care services**, and thus experience unmet health care needs (WHO, 2018).
- In many contexts, women and girls with disabilities are more likely to experience gender-based violence than women and girls without disabilities (WHO & UNFPA, 2019).

The role of Disabled People's Organisations

Disabled People's Organisations (DPOs) are representative organisations run by and for people with disabilities. DPOs have a mandate to represent the views and perspectives of people with disabilities and are key partners in development and associated research. They typically have a focus on advocacy and representation, although some may also provide services to their members or to people with disabilities more broadly.

DPOs can be local, regional, or national level organisations. They may be cross-disability, representing all people with a disability within a geographical area or community; or impairment-specific, representing people with a specific impairment such as people with hearing, vision, or psychosocial impairments.

DPOs are important partners in development and in guaranteeing that all research positively serves people with disabilities. DPOs ensure that research is inclusive of a variety of impairments and addresses the different challenges across the diversity of age, sex, gender identity and ethnicity factors.

Disabled People's Organisations and Research

The inclusion of DPOs in research and program planning is an ethical approach to **localisation.** Local history, politics, religion, culture, and other contextual factors shape the challenges facing different people, including people with disabilities. In different countries, regions and communities, people with disabilities may self-identify themselves in diverse ways depending on how disability is perceived and understood by the local social context. People with disabilities who are women, who are older or younger, who are part of an ethnic minority, who are gender-diverse or who live in remote areas or outside of the community, will have vastly different experiences and participation levels in life. Local DPOs are most likely to understand these contextual factors. Local DPOs can provide context and analysis of such intersections and additional needs.

There are many different ways that DPOs and their members can be involved in research. Strategies include:

- Identifying key priorities for research for people with disabilities.
- Sitting on advisory or steering committees.
- Providing formal or informal advice on barriers and approaches to disability inclusion within a particular context.
- Disseminating information about research to their members and other disability stakeholders.

- Partnering on research, which could include formally collaborating on research or involvement in components such as data collection, data analysis, reporting or dissemination of research.

It is important for researchers to remember that DPOs are often small and overstretched organisations, run largely by volunteers, with few paid staff and with limited budgets.

While it is vital to consult and engage with DPOs, the interest and capacity of individual DPOs to be involved in research activities will vary. DPOs will also have their own priorities and areas of focus and are likely to be more interested in engaging in research, which they consider relevant to their key priorities or their members' immediate needs. See **Case Study B**.

In implementing research, researchers need to identify ways to build the capacity of DPOs and support their priorities, rather than taking an extractive approach. Working with DPOs allows people with disabilities to self-determine the research process and its outputs. It directs how 'mainstream' projects can be inclusive, as well as how disability-specific research questions and products depict and describe people with disabilities. It also supports and builds the capacity of DPOs to use immediate in-country research in their own programs.

Researchers should also ensure that DPOs are recognised as experts on lived experiences of disability and are appropriately compensated for time and costs involved in advising on, or engaging in, research activities.

Dedicating a budget line to resource their collaboration in the research is an important step to acknowledge both current and historical power differentials "exist between researchers, local community, research beneficiaries, donors and other stakeholders" (RDI Network, 2020).

Case Study B: Partnering with the local DPO to understand the experiences of people with disabilities in SNV Nepal's *Beyond the Finish Line* project

Beyond the Finish Line is a water supply and hygiene promotion project being implemented by SNV Nepal and funded by DFAT from July 2018 to December 2022. A crucial step in this project is to understand the experiences of people with disabilities in accessing water and hygiene in target locations across Nepal.

To gather data on these experiences, a formative research project was conducted by SNV Nepal. CBM Australia provided project support by contributing disability-inclusion expertise to the SNV Nepal team and partner DPO. CBM Australia also provided technical support in collecting and analysing qualitative data.

Approaches to Inclusion

CBM Australia shared knowledge in developing disability-inclusive research methodology and findings. CBM Australia also strengthened the project team's capacity for working alongside people with disabilities.
CBM Australia facilitated training focused on disability awareness and inclusive research methods, which included making the informed consent process more accessible. Time was invested in training the research team members, including SNV Nepal staff and local DPO representatives.

The training modelled and established standards for inclusive behaviour and attitudes. It raised awareness of the discrimination (social and otherwise) that people with disabilities faced. The training also facilitated an environment for SNV staff and local DPO representatives to work and learn together.

After the training, SNV Nepal staff reported feeling more confident in their understanding of the barriers facing people with disabilities and working more effectively with DPO representatives.

Tools and Methodology Used

People with high levels of difficulty in functioning were selected to be the main research participants. This decision was made in order to document insights on the barriers faced by those who are most marginalised, and yet often left out of research processes, even in disability-focused research.

A qualitative approach was used to generate in-depth information, both to complement existing project information and to inform the direction of the promotion project. This approach was intended to generate findings to inform changes in practice to reach the most marginalised, with the assumption that the findings would also provide insights for those experiencing fewer degrees of marginalisation or exclusion.

The project team used the Washington Group Short Set of Questions (WGSS) to guide the selection of research participants. The WGSS is a set of questions designed for surveys or census questionnaires to identify people with disabilities. SNV Nepal worked with the local DPOs to select men and women with disabilities and carers of children with disabilities of different age groups, mostly with high levels of difficulty in functioning. Data collection tools included in-depth interviews, focus group discussions, key informant interviews, and accessibility audits in public school WASH facilities.

The in-depth interviews were found to be the most valuable in generating insights for the research team. The interviews included asking research participants to show the location of their WASH facilities and demonstrate how they would use them. These observations helped in deepening the research team's understanding on the experiences that people with disabilities and carers of children with disabilities had with WASH.

Research Advocacy and Learnings

In partnering with local DPOs and attending specific disability-inclusion training, SNV Nepal had the capacity to continue involving people with disabilities in the project implementation phase and strengthening district disability networks. In fact, SNV Nepal then was able to independently replicate the research process in a second district.

The research findings and experiences from this project have been used in advocacy to emphasise:

- The principles of 'leave no one behind' during World Water Day events
- The importance of training of project staff, global WASH sector team members, and local government representatives

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Key Resources and Further Reading:

- National Health and Medical Research Council. (2018) [PDF]. *Australian Code for the Responsible Conduct of Research* National Health and Medical Research Council. Retrieved 19 May 2020 from https://www.nhmrc.gov.au/sites/default/files/documents/attachments/grant%20documents/The-australian-code-for-the-responsible-conduct-of-research-2018.pdf
- RDI Network. (2017a) [PDF]. *From Evidence to Impact: Development contribution of Australian Aid funded research: A study based on research undertaken through the Australian Development Research Awards Scheme 2007–2016*. RDI Network. Retrieved 19 May 2020 from https://rdinetwork.org.au/resources/policy-and-practice-impact/ [PDF]

Entry Points: Background Principles and Assumptions

Entry Point 1: All research conducted must be aligned to key ethical principles and guidelines: respect for all human beings, research is for the benefit of others, research is conducted by relevant and qualified individuals, and is a fair and equitable process for all, especially for research participants.

Entry Point 2: People with disabilities hold equal rights to participating and accessing research information, actions, and activities. This includes respecting the lived experiences of people with disabilities, and their right to autonomy and self-determination in research projects and development activities.

Entry Point 3: Outdated models of conceptualising disability include the 'charity model' which sees people with disabilities as helpless victims, and the 'medical model' in which people with disabilities are seen as medical objects to be cured or 'fixed'. Both models disregard that people with disabilities have agency. Conversely, a 'rights-based approach' to disability recognises the need to a shift in society to characterise people with disabilities as just another way of being.

Entry Point 4: Disability-inclusive development is an approach to international development that seeks to ensure people with disabilities are fully included in development processes. This approach is endorsed and supported by DFAT.

Entry Point 5: With a majority of people with disabilities living in low-and-middle-income countries, the effects of having a disability and living in poverty exacerbate each other. A person with a disability is likely to face discrimination in receiving formal schooling, in finding a job and/or in increased healthcare costs. A person living in poverty is more likely to experience disability due to lack of access to proper healthcare, food security and safe(r) living conditions.

Entry Point 6: Local Disabled Peoples Organisations (DPOs) have a deep understanding of context and extensive networks, including working relationships with local people with disabilities and local communities. They should be engaged in the design and implementation of research projects.

Section Two: Ethical conduct, processes, and informed consent in research

Summary: This section details the need and discussions required for ensuring robust ethical processes in the design and implementation of disability-inclusive research projects. It acknowledges that people with disabilities both have agency *and* require additional consideration to ensure their rights are protected. This is due to power differentials between people with disabilities, people without disabilities, researchers, donors, and other development actors.

"Fundamentally, ethical research principles are about the relationship between researchers (those who conduct, fund and commission research) and research participants."

– ACFID & RDI Network (2017)

Disability-inclusive development seeks to **genuinely** include the needs of people with disabilities in all facets of the research process. It is not a tokenistic or 'Band-Aid' approach to addressing systemic discrimination. This is in addition to all the other challenges in working with low-and-middle-income countries due to historical and current disparities in wealth, power, political interest, and resources.

Research conducted in LMICs, in relation to people and/or children with disabilities raises distinct ethical, moral, social and political issues, and challenges.

The power imbalance and potential for abuses in trust is heightened between researchers and participants, especially when the research is linked to policy and programming decisions.

Unintended negative consequences can arise, such as: social repercussions for the people with disabilities for participating, coercion from close family members and/or carers of people with disabilities to participate, and use of research to further marginalise and isolate people with disabilities.

There is also a heightened chance of **othering** people with disabilities when staff and project members lack disability-awareness (and cultural-awareness) training. It is possible to reinforce existing unjust social relationships and stereotypes through small, inadvertent actions that cause a negative experience for people with disabilities participating in the research activities (Kattari, 2018).

To ensure that the entirety of the research process adheres to the principles of ethical research, it is an imperative to collaboratively assess ethical considerations during all phases. The research design phase is critical in establishing the standard for all other activities to follow.

Any research involving people requires research teams to think through all ethical considerations relevant to potential participants, team members and the wider community. See **Figure 4**.

Ethical considerations are influenced by many factors, including:

- The research focus (e.g., WASH, health, experiences of violence)
- The methods (e.g., anonymous survey versus community consultations)
- The context (e.g., well-resourced urban setting, remote rural setting with few resources, post-disaster setting)
- The study populations (e.g., community leaders, young people, people who have experienced trauma, or people engaged in illicit activities)

Gaining ethics approval

Researchers should be aware of, and follow any national ethics processes within the country where the research will take place. Researchers should also undertake all relevant ethical review processes through the institution of the lead researcher or research team member (ACFID & RDI Network, 2017).

Generally, institutions such as universities, hospitals and some international organisations, have their own ethical approval processes which requires researchers to submit an ethics project application form detailing the research, its ethical considerations and how the research team plans to uphold the core principles of ethical research. The application is then reviewed by the committee who will either approve the research or request clarification on any ethical issues they identify. Processes in both the country of the research institution, and the country where the research will take place, should be adhered to stringently.

The RDI Network website features guiding materials for different regions across the globe. **See:** https://rdinetwork.org.au/resources/conducting-research-in-the-region/

When research is proposed to be conducted in a country with no / without any established ethics committee or institutional review board in the country of the principal investigator should take into account the local laws and customs of the communities in which the research is proposed to be conducted (Dalton & McVilly, 2004).

Figure 4: Ethics in the research cycle

Furthermore, where no national ethical approval process is available, it is expected that the principles for ethical conduct will still be applied (see ACFID & RDI Network, 2017). Developing the ethics application with local partners will enable the research team to identify and discuss local ethical considerations. See **Appendix 1** for a checklist of considerations.

Considerations for the research team:

- **Identifying appropriate DPOs to partner**: Often power relations can be influenced by differing priorities. This is the same with the organisations representing people with disabilities. Ensure that the local partner organisation truly reflects the needs and voices of the disability community, and not local agendas for power and status. If this happens, perceived hierarchies of importance are reinforced, and consequences compounded when resources are scarce, and time is limited.

- **Identifying appropriate and available disability-training for staff and project team**: As a society that exalts the experiences of people without disabilities, it can be challenging to address the internal (false) dialogue on disability, ability, and personhood. Often, actions that are well-intended, inclusive, and accepting of people with disabilities can reinforce that people with disabilities are 'different and alien' (othering). They can also impose stereotypes on helplessness, violate personal privacy, and/or patronise (Sue, 2010). Successful inclusion of people with disabilities in programs is only likely if organisations review and revise their own internal policies.

  However, it is noted that disability-training needs to be done within the existing cultural context. Disability-inclusive practice needs to permeate within all aspects of operations, from human resources, to complaints procedures and communications standards. This requires leadership and staff to be open to implementing and modelling such changes. Therefore, identifying and bridging the strengths of both the local community and local disability community underpins effective, inclusive practice.

- **Identify reasonable accommodation to embed into the research process.** People with disabilities may have diverse ways of acknowledging their abilities depending on how disability is perceived and understood by the local social context. Enabling reasonable accommodation for *all* project members to use may enable more people with disabilities to participate without feeling 'singled out' or stigmatised. Examples of these accommodations are; having more room between workspaces, using large print for all written materials, and using plain language for all communications.

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- **Developing appropriate and responsive feedback channels for staff with disabilities:** Whilst aiming to embed disability-inclusion into your systems and processes, some project staff may need more support. It is important to develop a procedure that enables team members with disabilities to give feedback on their participation and sense of belonging. It is necessary to evaluate and refine your systems and processes for genuine inclusion of people with disabilities.

Considerations for potential participants:

- **Identifying appropriate and available referral pathways for research participants**: If conducting research on access to immunisation for children, for example, it may be useful to identify if *and* when services may be required to follow up with the participants. It is essential that you discuss the referral pathways with all relevant services that may be involved, ensuring they have the capacity and resources to provide services to people with disabilities and their families. If services are not available, it is important that the research team does not raise expectations and ensures clear communication with potential participants about the benefits and risks of the research. See **Case Study C.**

- **Developing appropriate distress or follow-up protocols:** Whilst researchers aim to not cause harm, some participants may become distressed when talking about their experiences. It is important to develop a protocol for what to do in these situations. This may involve checking in with participants throughout the interview to make sure they are comfortable, stopping the interview and, if necessary, providing psycho-social support. It may also include following-up with the participant shortly after the interview to see how they are doing and supporting the participant to access further support. It is also important to identify the types of further support available and accessible, such as a research team counsellor, the participants' own established support networks, or referring the participant onto available local services.

- **Ensuring there is no financial burden associated with participation:** People with disabilities and their families, including carers, may experience financial barriers associated with limited accessible public transport, they may lack resources to afford childcare, or lose wages and livelihood opportunities whilst participating in the research. It is important to understand these costs and find alternative ways to engage with individuals, or to cover for transport expenses and childcare costs.

- **Ensuring the privacy of participants:** Depending on the context or research topic, researchers may need to work in small teams to ensure the privacy of the participant. For example, if you are interviewing women with disabilities about their access to sexual and reproductive health and a participant has chosen to be interviewed at home but there are other family members around, you may need one member of the research team to be with the interview participant, while other research team members engage with the family members in a different area to ensure the participant has privacy during the interview. Such considerations need to be clearly discussed with all research team members during training and throughout the research.

- **Providing accessible information about research.** All communication related to the research should be provided in accessible formats. This is relevant whether people with disabilities are participating as researchers and/or as research participants. Information should be shared in a way that participants can understand. Consider all potential barriers to understanding and provide information through a variety of formats depending on these barriers. This may mean sharing information in Braille, large font sizes, in the participant's first language, or through a sign language interpreter. It is also important to consider the tone and language used to describe experiences and people with disabilities. See **Appendix 4** for tips on communicating with people with a variety of impairments.

Comprehension difficulties that may be associated with cognitive disabilities may also be addressed by using easy-to-understand **Plain Language Statements.** Easy-to-understand forms for informed consent need to avoid jargon and use simple, direct language. The use of visual cues and/or practical demonstration of research procedures may also be needed. Also, it may sometimes be necessary to seek consent from a trusted person for those who may themselves be unable to express consent (e.g., plain language may not be enough for some people with a moderate to severe intellectual disability).

See **Appendix 5** and **6** for templates.

Further considerations on **informed consent** are discussed later in this guide.

Case Study C: Identifying appropriate and available referral pathways for research participants

A research team was interested in finding out about referral pathways for women with disabilities who had experienced violence in a Pacific country. In order to do so, the research team first mapped **what** services were available, then **where** the services were located, and finally **how** the service would support women with disabilities.

To determine the accessibility of the identified services, the research team met with service providers to discuss potential situations and scenarios. During these meetings, service providers indicated that they were unsure about how to best support women with disabilities.

With this information, the research team was then able to work with the service providers to build their capacity to work with women with disabilities. Afterwards, the service providers then felt comfortable in their abilities to receive referrals from the research team and support the women referred. The confidence of the service providers was measured using a Knowledge, Attitudes, and Practice (KAP) survey.

Key Resources and Further Reading:

- ACFID, & RDI Network. (2017). *Principles and Guidelines for ethical research and evaluation in development* [PDF]. ACFID. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2017/07/G2321_ACFID-RDI_PG2017_WEB_compressed.pdf
- **Appendix 3:** Checklist for participant information form and participant consent form
- **Appendix 4:** Tips on communicating with people who have a variety of impairments
- **Appendix 5:** Template for easy-to-understand Plain Language Statement participant information sheet
- **Appendix 6:** Template for easy-to-understand Plain Language Statement consent form. This is an informed consent process that uses true and false questions to determine whether the potential participant has understood the information and chooses to participate.
- RDI Network. (2017b). *Conducting Research in the Region: Ethics Approval Processes*. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/resources/conducting-research-in-the-region/
- TEDxSydney. (2014). *Stella Young: I'm not your inspiration, thank you very much* [Video]. Retrieved 8 April 2020, from https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much?language=en

Understanding Informed consent

All people with disabilities should be assumed capable of making their own decisions. This applies to people with all types of impairments, including those with cognitive or intellectual impairments or a psychosocial disability. **Informed consent** is when an individual freely gives permission to participate in an activity. In the context of research, this means that an individual voluntarily chooses to participate in research and/or research activities with complete understanding of the process, possible consequences, risks, and benefits.

Ensuring informed consent is gained from all individuals is a key aspect of the research design process. As Article 21 of the CRPD states:

> "States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice" (UN, 2006).

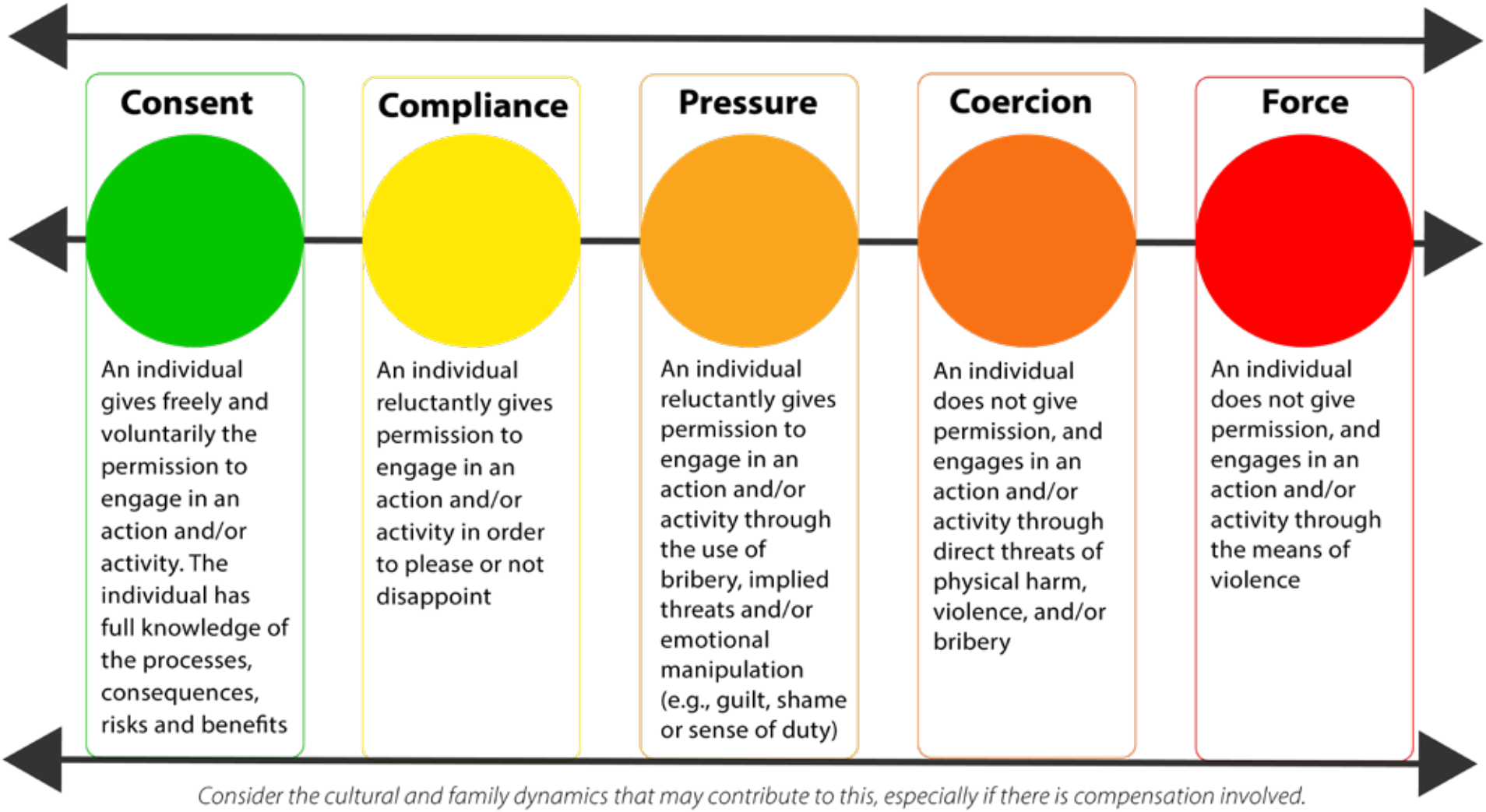
It is also pertinent to remember that consent exists in a continuum.

See **Figure 5**.

Both historical and current disparities in wealth, power and resources between development researchers and communities from LMICs means careful consideration of the consent process must be taken into account.

Understanding that consent is not a simple, binary process highlights the importance of ensuring accessible and inclusive consent processes. Enabling people with disabilities to make their own choices about whether to participate, and if so, how they participate in research is crucial to disability-inclusive development. This also includes welcoming people with disabilities to draw on support mechanisms during research if needed (UN, 2006).

Figure 5: The Consent Continuum



Consider the cultural and family dynamics that may contribute to this, especially if there is compensation involved.

Enabling informed consent for potential participants

Part of enabling the informed consent process is determining if all potential participants understand the information provided to them about the research; what is involved in participation, and any benefits or risks associated with participation. If a person can provide informed consent but is unable to read and sign a consent form - for instance, if they have a vision impairment - they may provide verbal consent. Where a verbal consent process is implemented, this should be formally documented and witnessed by the researcher.

For informed decision-making, potential participants must be aware of the nature of the research. Information provided should include:

- An outline of the research
- Any potential benefits, potential risks, or adverse consequences
- A description of how the participants' information will be stored and who will have access to it
- A statement explaining the person's rights to decline participation, and if they agree to participate, their right to withdraw at any stage during the research
- A statement explaining that there will be no adverse consequences should they choose to decline participation or withdraw consent

In some circumstances, the people we seek to include in research may not be able to express informed consent themselves (for example, some people with severe intellectual disabilities). Accordingly, informed consent may require support for the decision from a person they trust, or even seeking consent from someone else (e.g., a trusted family member or support person). Researchers need to consider and clearly describe in their research design how they will determine a person's capacity to consent to the research, who will make this decision, and the criteria on which it is based.

It may be useful to develop a decision tree for use in the field that outlines consent and interview support procedures. See **Appendix 7** for an outline of a decision tree for determining the process for informed consent and support to participate in research.

Determining if informed consent can be gained from potential participants

People with disabilities should have risks, confidentiality and the purpose of the study outlined with the clear option to withdraw from research at any point (or with any limits to this fully explained). The consent process should include information on potential benefits that the research may have to people with disabilities. Informed consent to participation in research should be sought either from:

- The participant, or
- A trusted person close to the participant (e.g., trusted family member, guardian, or support person)

Whether a person has the capacity to consent depends on the nature of their condition, including fluctuations in their condition and the complexity of the research.

Ideally, consent should also be witnessed by a person who has the capacity to fully comprehend the potential benefits and risks of the research, who is independent from the research team, and, where possible, knows the participant and is familiar with their condition. Where potential participants are especially vulnerable, consideration should be given to the appointment of an advocate for the participant. However, participant resistance, discomfort, or refusal to participate must be respected at all times, regardless of the views and opinions of others in the consent process.

The people closest to and trusted by these individuals (e.g., family members, a guardian or a support person) may be best placed to communicate the research to the individual, and ascertain whether they are willing and able to participate in the research. Refer to **Appendix 6** for an example of an informed consent process that uses true and false questions to determine whether the potential participant has understood the information and chooses to participate.

It is crucial to ensure adequate time and resources are available to engage with potential participants (and a support person if required) to determine whether informed consent can be gained.

To determine whether a person can provide informed consent, the following considerations should be made:

- Can they interpret and express the information shared to them in their own words?
- Do they remember the information shared to them?
- Do they understand their right to decline participation with no adverse consequences to them?
- Do they understand any associated risks or benefits of the research activity?

Determining support systems needed in decision-making processes

There may be times where researchers and the project team need to clearly outline the procedure for assessing whether a person with a disability needs extra support. Sometimes, it can be difficult to determine whether a person can or cannot give consent. Sometimes a person is unable to provide informed consent but otherwise demonstrates a wish to still participate.

If another person is involved in the decision-making process, it is important to ensure genuine assent to participate is obtained from the participant. The refusal to participate must be respected. Even if a parent or caregiver gives consent, the person **must not** be coerced to participate in research activities against their will or have someone speak on their behalf without their consent. A researcher **must not** continue to collect data from any individual if there are concerns of lack of genuine consent.

In some cases, a person's spouse, parent, or legal guardian needs to be consulted. If relevant to the local laws and cultural context, community leaders should also be consulted. If a research team thinks proxies will be used at any stage, it is important that this is communicated within the ethics process. Alternatively, the potential participant may be happy to have someone support them during the research process (e.g., sit in on interviews or respond on their behalf). If this is the case, the research team will need to determine the nature of the questions asked. Questions may need to be assessed for appropriateness for a proxy to answer. At all stages, it is important to document these processes, including highlighting if proxies have been used when reporting on findings.

Local DPO partners may be able to provide cultural guidance on the most suitable way for researchers to respond in these circumstances.

This may require the lead researcher or field supervisor to visit the family with the DPO partner to discuss the research and the ethical requirement for informed consent protocols to be strictly followed. This may also lead to carefully explaining to the participant and their family the reasons why participation in the research process can or cannot be continued. Role-playing these scenarios with research team members during training and providing support and supervision in the field will help to mitigate some of these potential issues.

Determining appropriate methods of communication

Where appropriate, background information, consent forms and research tools used for gaining informed consent and data collection should be provided in varying formats. These include, but are not limited to:

- Plain language in the local language
- Pictorial format or using visual cues
- Local sign language
- Large print, Braille and/or audio

Providing accessible materials to include people with disabilities should be based on individual preference and, when possible, it would be pertinent to discreetly ask potential participants their preferences in advance. This is also where local DPOs can be involved in the research process; to guide best-practice for researchers.

Where applicable, communications can also be developed to support people and legal guardians to ensure that both the potential subject and support person are fully informed. This will assist the support person in communicating the risk, confidentiality, and purpose of the research with clarity.

Key Resources and Further Reading:

- **Appendix 6:** Decision tree for determining the process for informed consent
- CBM. *Disability Inclusive Development Toolkit* [PDF]. Retrieved 8 April 2020, from https://www.cbm.org/fileadmin/user_upload/Publications/CBM-DID-TOOLKIT-accessible.pdf.
- CHANGE. *How To Make Information Accessible: A guide to producing easy read documents* [PDF]. Retrieved 8 April 2020, from https://www.changepeople.org/getmedia/923a6399-c13f-418c-bb29-051413f7e3a3/How-to-make-info-accessible-guide-2016-Final
- Inclusion Australia. (2020). It's My Choice Toolkit [PDF]. RMIT University and Inclusion Design Lab. Retrieved 8 April 2020 from https://inclusionmelbourne.org.au/resource/choice/
- Support My Decision. (2018). Tools and Resources for Making Decisions for People with Disabilities [Website with PDF downloads]. ADACAS Advocacy. Retrieved 8 April 2020 from https://support-my-decision.org.au/resources-2/

Conducting ethical research with children with disabilities

There are many specific issues to consider around inclusion of children with disabilities in research. In addition to the considerations listed earlier in this section, working with children with disabilities requires innovation and creativity to ensure inclusivity and informed consent. Both consent from the child and their parent, guardian and/or carer is necessary.

This segment showcases a case study of working with children with disabilities, and a set of key resources for supporting the involvement of children with disabilities in research. Some of these resources were developed by Deakin University in partnership with Papua New Guinea Assembly of Disabled Persons (PNG ADP), Save the Children PNG and Save the Children Vanuatu, and the support of the Vanuatu Disability Promotion and Advocacy Association.

Most importantly, it highlights the value of overt inclusion in the planning process **how** the researcher will engage with a child with a disability in the process of data collection. This may involve asking a modified or simplified version of interview questions, or using alternative participatory methods, such as drawings or a photo library. See **Case Study D**.

Again, it is important to document these processes at all stages, including highlighting if parents, guardians and/or carers have been present and/or have answered on their behalf when reporting the findings.

Case Study D: Inclusive approaches to working with children with disabilities in community development

A child-focused development organisation wanted to understand more about the lives of children with and without disabilities to inform the inclusion and mainstreaming of children with disabilities within a specific community development setting.

The study objectives were to:

- Explore the understanding of disability and the rights of children with and without disabilities as understood by key actors in the community. These included: government, development partners, Disabled People's Organisations, non-governmental organisations, families, or caregivers of children with and without disabilities, and children with and without disabilities themselves.
- Examine access to services and programmes for children with and without disabilities and their families, including social protection, social inclusion, health and rehabilitation, education, WASH, and child protection.
- Explore enablers of, and barriers to, the inclusion and mainstreaming of children with and without disabilities within the community development program.
- Develop recommendations to promote the inclusion of children with disabilities within the community development setting.

Approaches to Inclusion

To ensure that the organisation met and served local community needs, they partnered with an academic institution and the local DPO to implement a situational analysis. The local DPO members were engaged as co-researchers and worked with these partners to shape the scope of the research. This included consulting on ethical considerations and supporting the implementation of the research project within the community.

Furthermore, ethics approval was obtained and vetted by the academic institution with local approvals also obtained through the relevant government Ministries and community leaders.

Tools and Methodology Used

To gain a comprehensive understanding, both a desk review of relevant literature and available data was completed, as well as qualitative interviews. Interviews and Focus Group Discussions were conducted with all key actors, including the children.

The study team ensured children with disabilities were enabled to participate in the study as key stakeholders by:

- Using easy-to-understand plain language statements and consent forms to obtain informed consent. These were obtained from a parent or carer.
- Utilising participatory interviews and small group discussions with children with and without disabilities. Existing participatory tools for children with disabilities were adapted for the local context to help children talk about what is important in their lives (e.g., what makes them happy, what makes them sad).
- Activities were developed to ensure children of different ages and with different kinds of impairments were able to participate. These activities included:
    - *Drawing* – whereby a child is invited to draw pictures
    - *Story in a bag* – whereby a child chooses items from a bag filled with a selection of objects
    - *Sound library* – whereby a child listens to short audio recordings of local sounds
    - *Photo library* – whereby a child selects context specific photos from a photo library

The study team worked together to analyse and contextualise the data. Findings were presented back to the community. The partners were then able to work with the community to determine future strategies for inclusion and mainstreaming of children with disabilities in the community.

Figure 6: Working with children, with and without disabilities in the Philippines. Photo by Avel Chuklanov on Unsplash © 2018

Key Resources and Further Reading:

- Australian Market & Social Research Society. (2017). *Guideline on interviewing children and young people* [PDF]. AMSRS. Retrieved 8 April 2020, from https://creative.vic.gov.au/__data/assets/pdf_file/0019/354052/AMSRS_Guide2017-Interview-children-and-young-people.pdf
- **Factsheet 3:** How can we help keep children and young people with disabilities safe? From Children and Young People with Disabilities Australia. Retrieved 14 April 2020, from https://www.cyda.org.au/LiteratureRetrieve.earchResult&SearchID=13157010&ObjectID=217942&ObjectType=6
- Jenkin, E., Wilson, E., Murfitt, K., Clarke, M., Campain, R., & Stockman, L. (2015). *Inclusive Practice for Research with Children with Disability: A Guide* [PDF]. Deakin University. Retrieved 8 April 2020, from http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf
    - This guideline is a set of resources for supporting the involvement of children with disability in research. It includes an overview of the principles of inclusive research with children with disability and further guidance on ethical considerations relevant to research with disability. Tips for communicating with children with disability, and using participatory methods and activities are also included.

Entry Points: Ethical conduct, processes, and informed consent in research

Entry Point 1: Consent is not binary; careful considerations must be contemplated to ensure that a potential participant is not being pressured or coerced into giving assent. Cultural considerations and power differentials need to be examined to ensure genuine consent.

Entry Point 2: Informed consent means that potential participants are knowledgeable about all aspects of the research process, including risks, rewards, benefits, and dissemination of information.

Entry Point 3: Enabling informed consent when working with people with disabilities requires determining the appropriate communication methods of collecting consent, the ability of the potential participant to give consent and identifying necessary support systems available to people with disabilities.

Entry Point 4: Working with children with disabilities requires further deliberation on ethical processes, including determining the appropriate methods of communication required to help children, their parent and/or carer to **all** understand the research process.

Section Three:
Practice Across the Research Cycle

Summary: This section outlines key phases of the research cycle and important factors and components to consider within each phase to enable research. The key phases covered include **Planning**, **Design**, **Implementation**, and **Dissemination**.

It is important to note that many components, such as capacity building, often occur across all phases of the cycle. Sequencing of research components may also differ, depending on the context and levels of existing engagement and partnerships.

A checklist for a disability-inclusive research design cycle can be found in **Appendix 1**.

"Co-operative planning integrates all relevant stakeholders. It fosters shared and equal decision making and research processes by creating a systematic project design."

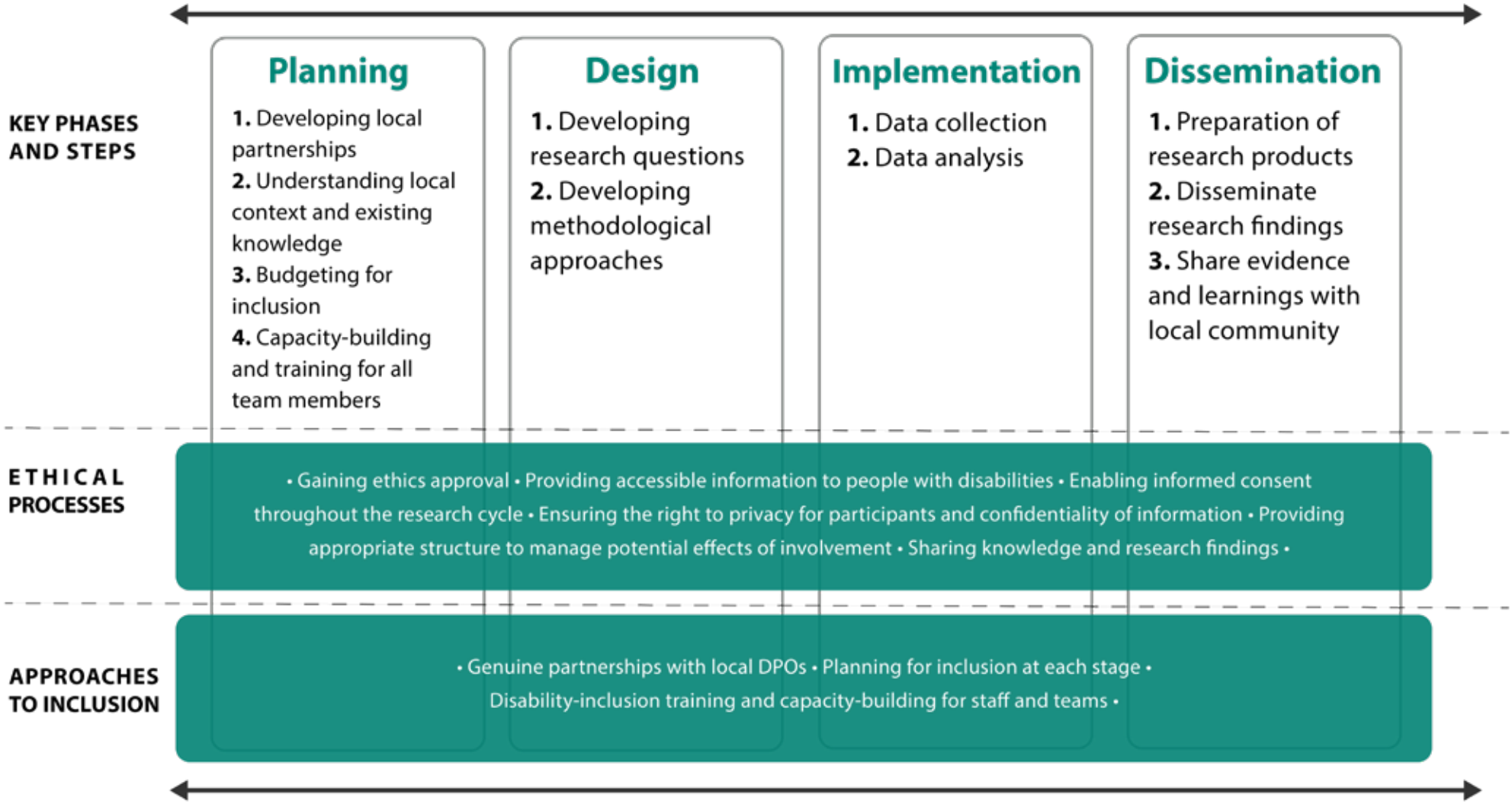
- Nchole Georgeou and Charles Hawksley, RDI Network (2020)

For development to break down entrenched inequalities and empower local communities, it is essential that development researchers and practitioners have a greater awareness of the rights, needs and strengths of people with disabilities. This also enables current, relevant, and reliable research (data and evidence) to be used by programming staff and policymakers.

The research cycle has four phases **Planning**, **Design**, **Implementation**, and **Dissemination**, which can easily be adjusted to ensure disability-inclusivity.

See **Figure 7.**

Figure 7: The Research Cycle Process Chart



Planning Phase

There are four key steps in the planning phase of research. The steps included are **1)** Developing partnerships; **2)** Understanding the context and existing knowledge; **3)** Planning for inclusion across all stages of the research; and **4)** Capacity building approaches for disability-inclusive research. The sequence of steps will depend on the context and degree of existing engagement and partnerships.

Step 1: Developing partnerships

Partnerships are a key component of any development and research program. Developing partnerships with people with disabilities and their representative organisations is central to research. Refer to **page 40** for ethical considerations when partnering with a local DPO.

Partnerships may be with local DPOs that already have an existing relationship with the research organisation. If existing partnerships are not available, consider ways to identify local DPOs and build a relationship with them.

It may also be worth considering if existing local partners have relationships with community DPOs. It is important that the local DPOs have an interest in the area of research and want (and can) form a research partnership. Ways to identify potential partner DPOs include:

- Consulting with existing development partners and networks or local government bodies.
- Via information provided by international organisations or umbrella bodies of DPOs. Key bodies include:
    - **International Disability Alliance** (IDA) is an umbrella organization of eight global and six regional organisations of persons with disabilities that focus on improving awareness and rights of people with disabilities across the world. Global and regional organisational members often represent a number of local DPOs and may therefore be a useful source of information on which local DPOs exist in various contexts. See: http://www.internationaldisabilityalliance.org/content/ida-members
    - **Disabled People's International** (DPI) is a worldwide network promoting the full and equal participation of people with disabilities. It has Member National Assemblies in seven regions and a presence in 139 countries. See: http://www.disabledpeoplesinternational.org/
    - **Pacific Disability Forum** (PDF) is the umbrella body for DPOs in the Pacific. See: http://www.pacificdisability.org/Members/Our-Members.aspx

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Once potential partners have been identified, initiate and highlight opportunities to share respective research ideas, knowledge and expertise, and opportunities for collaboration. This process takes time and it is often necessary to resource DPOs to enable their engagement. Some DPOs may already have had opportunities to collaborate in research, whilst for others, research partnerships may be new. It is important to clearly articulate the benefits and challenges of such partnerships, as well as to collaboratively determine shared strengths and resources.

It may be useful to engage in a **stakeholder analysis** and **mapping** to understand the different capacities and strengths of DPOs. This will be further elaborated in **Step 2** of the planning phase.

Researchers and local DPOs need to work together to establish the foundations of the partnership and the mechanisms to review and adapt partnership processes as required. This includes determining any capacity-building required and allocating budget lines to enable DPOs to participate. Likewise, it is necessary to collaboratively establish a research agenda to define the purposes of the research, to identify the areas to be researched, scope, and framework for making decisions, and to include a process to resolve any conflicts that may arise.

Formalising the partnership through a **Partnership Agreement** will help promote a shared understanding of the values and objectives of the partnership as well as ways of working.

When a collaborative research activity is identified, then all parties need to determine specific roles and responsibilities of each partner and how these functions will be resourced. This can range from co-production, to shared responsibility for one part of the project, to limited interactions like consultations and advisory positions.

See **Figure 8.**

Alongside partnerships with people with disabilities and their representative organisations (DPOs), research teams may include partnerships with local or regional academic institutions that are focused on or have an interest in the area of research to be covered.

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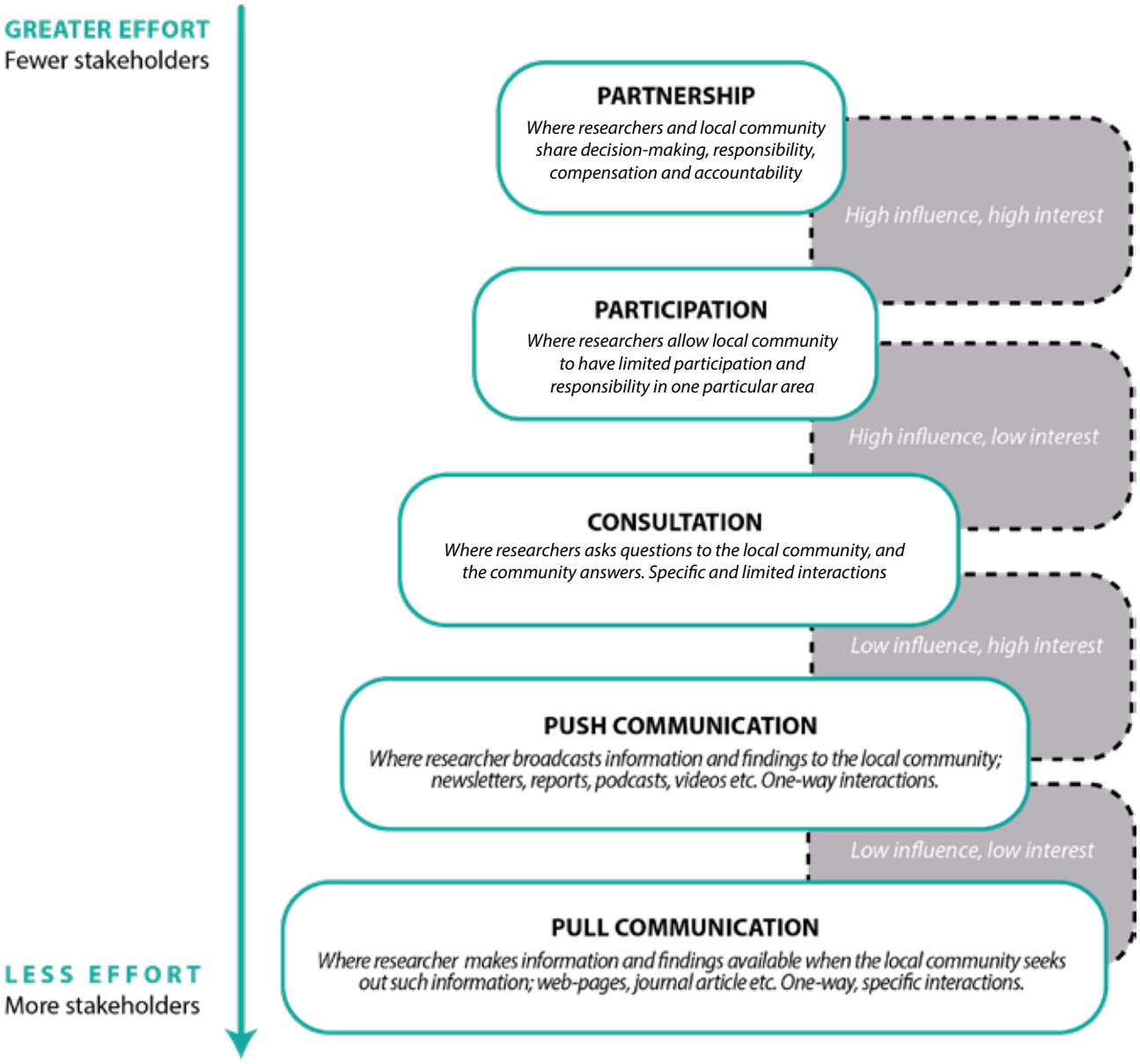
Figure 8: Stakeholder Engagement Pyramid



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For example, non-governmental organisations and development programs working in communities of interest, and relevant government bodies and services. Other stakeholders to consider include:

- Local and international experts with disabilities and/or experts in the area of research and/or disability
- Families of people with disabilities
- Community and religious leaders
- Representatives across all levels and relevant areas of government
- Disability-specific and mainstream non-governmental organisations, donors, and development partners
- Organisations who already do or should include people with disabilities in their work
- Service providers (e.g., health, social services)
- Education representatives (e.g., teachers, training institutes)
- Academics

It is important that all partners are on board with enabling research. Awareness-raising and capacity building of all research partners may therefore be an essential starting point. Please see **Case Study E**.

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Case Study E: Developing and Strengthening Partnerships with the W-DARE project

W-DARE (Women with Disability taking Action on REproductive and sexual health) was a three-year program of participatory action research that aimed to improve the sexual and reproductive health (SRH) of women and girls with disabilities in the Philippines. It was conducted in partnership by the University of Melbourne (Australia) and De La Salle University (Philippines), and with community partners WOWLEAP, PARE, Likhaan Center for Women's Health, and the Center for Women's Studies Foundation at the University of the Philippines.

Approaches to Inclusion

W-DARE brought together co-researchers with disabilities, DPOs, SRH service providers, local government unit representatives, local academic partners (social research and gender researchers) and Australian-based researchers. All partners had the skills and knowledge relevant to researching the sexual and reproductive health (SRH) experiences, needs and priorities of women with disabilities. But by bringing together many different professionals, the project also acknowledged that each partner had varying levels of experience in designing and delivering capacity building approaches that the research team could both draw on and build upon.

For example, the SRH service providers had worked with their communities to promote SRH understanding for decades, yet had less experience working with women with disabilities. Co-researchers with disabilities were able to share their lived experience of disability but had limited experience engaging professionally with SRH. Australian-based researchers had experience with qualitative and quantitative research methods but were not familiar with the contexts of where the research would take place.

Tools and Methodology Used

The first phase of capacity building activities for the W-DARE team was co-delivered with local partners and included ethical, methodological, and contextual components. The W-DARE team, which included men and women with disabilities, were then supported and supervised by more experienced local academic partners.

The activities included:

- Introduction to disability-and-gender-inclusive research
- Qualitative research methods training
- Implementation of the Rapid Assessment of Disability training
- Consolidation of research methods workshop

The second and third phases of the W-DARE project included supply-and-demand side capacity building approaches. Five Participatory Action Groups (PAGs), consisting of women with and without disabilities, and one parent group were formed. These groups met for a series of ten sessions to improve their knowledge and awareness of SRH and their rights to quality services.

The groups were facilitated by existing W-DARE co-researchers with disabilities and newer team members with disabilities. This enabled more experienced team members to develop their facilitation and research skills whilst mentoring newer team members.

"I have been involved in the women's movement as a researcher for many years, and I am ashamed to say that I never really thought about women with disabilities." *- (Academic partner)**

Partner SRH service providers from the W-DARE team worked with the PAGs to design sessions on SRH awareness-building by facilitating groups to visit SRH service providers together, map out their transportation methods and discuss the service provided by each different service. The W-DARE team also developed inclusive ways to teach women about SRH by using solutions with different smells to help women with vision impairment use their olfactory senses to learn about the different signs and symptoms of sexually transmitted infections.

* *This quote has been included to demonstrate the impact and attitude change after working with people with disabilities. The authors acknowledge that such phrasing may be othering and ableist in nature.*

Learnings

The first phase of the research included several participatory workshops designed to identify and share existing skills and knowledge. It also identified gaps to address. This enabled the W-DARE team to map out ongoing capacity building needs and approaches. The collaborative approach helped build trust between the research partners and enabled team members to share their knowledge in a safe environment.

It also provided an opportunity for co-researchers with disabilities to demonstrate their capacity. This in turn enabled other team members to reflect on how they had previously included or excluded people with disabilities in their work.

"It has been a steep learning curve for me, I never worked alongside women with disability before. I mean I was really surprised; they can really do it."

- (Academic partner)†

In the second and third phases, the PAGs helped the W-DARE team to further develop their confidence in designing disability-inclusive training. Particularly in creating large-scale SRH training, which W-DARE then delivered to a wider group of governmental and non-governmental service providers. However, W-DARE did find it challenging to ensure that women with psychosocial disabilities were included in the early stages of the project. To address this, the Australian research team worked closely with a researcher with a psychosocial disability to design and implement a nested research activity to better understand the specific needs of women with psychosocial disabilities and how W-DARE could better include them in its ongoing activities.

† *This quote has been included to demonstrate the impact and attitude change after working with people with disabilities. The authors acknowledge that such phrasing may be othering and ableist in nature.*

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Key Resources and Further Reading:

- Carroll, A., Davar, B., Eaton, J., Catherine, R., Cambri, J., Devine, A., & Vaughan, C. (2016). *Development Bulletin 77: Promoting the rights of people with psychosocial disability in development research and programming* [PDF] (pp. 25-30). Australian National University. Retrieved 8 April 2020, from https://crawford.anu.edu.au/rmap/devnet/devnet/db-77/db-77-ee-3.pdf
- W-DARE. (2015). *A summary of initial findings and pilot interventions* [PDF]. W-DARE. Retrieved 8 April 2020, from https://wdare.files.wordpress.com/2015/06/w-dare-community-report.pdf
    - For more information on other approaches included in the W-DARE including peer-to-peer exchanges between local government units, refer to the W-DARE report on the summary of initial findings and pilot interventions.

Step 2: Understanding the context and existing knowledge

A critical step in inclusive research is to understand the local context in which the research is situated. Understanding the context and identifying local relevant sources of information is often most effectively done in consultation with research partners. It is also pertinent to synthesize and assess the **existing** knowledge and available evidence relevant to the area of research.

Relevant research papers and reports may be identified through a formal literature review and/or through discussion with local DPOs, key stakeholders and their networks.

They may include quantitative and qualitative research studies, as well as programmatic research conducted for the purpose of monitoring and evaluation. This also needs to include any relevant research of disability. This helps ensure that research does not replicate something that has already been done before. It also helps identify the gaps in research and knowledge. This type of work is often called **secondary research** or, colloquially, as a **desktop review** or **desk research**.

Secondary research is also useful in refining research priorities, informing appropriate methodology, and identifying the relevance of the research findings. This then informs how the research can be utilised to help inform ongoing development programming.

The following are some guiding questions that can help synthesise available information to identify research for the analysis:

- What is the relationship between disability and the area of research?
- What is known about the experiences of people with disabilities and their inclusion within the area of research focus?
- Which factors facilitate or inhibit the inclusion of people with disabilities in the area of focus?
- How do various stakeholders see disability inclusion and how does this influence policy and programming?
- What are the research gaps and how can addressing these gaps improve inclusion of people with disabilities?

To ensure research relevance and impact, consider these other key areas:

- **Stakeholder analysis and engagement:** Early identification and engagement of stakeholders who are involved in, and/or are relevant to the area of research and disability is incredibly valuable. Gaining and establishing trust and support for the research will depend on the relationships and expertise available for the project. The project scope will also draw on stakeholder knowledge and experience. Involving local DPOs and/or researchers with disabilities will inform diverse research thinking, and will model disability-inclusive practices to other local communities, organisations and partners.
- **Policy analysis:** This involves analysing the laws and policies relevant to the area of research and to people with disabilities. It also considers how these laws and policies are implemented across the different levels of government to influence the experiences of people with disabilities. For example, if the research is focused on education, the research team would need to firstly understand if children with disabilities are **1)** included (or not), and **2)** how they are included (or not) in educational policies. It would then be necessary to understand how educational policies are resourced, operationalised and monitored, and whether the educational needs and outcomes of children with disabilities are adequately supported through all of these processes.

- **Programmatic and service mapping:** Mapping of relevant programs and services relevant to the area of research helps to understand what services are available (or not available) for people with and without disabilities. It will also be important to map how these programs and services operate within a system. With the support of local DPOs, this information can then be used to understand the experiences of people with disabilities within systems and how inclusion could be improved.

  This process also allows research teams to engage with local programs and services to identify useful programmatic data and documentation. For example, if you are researching on improving access to early intervention for children with disabilities, it is important to map what services are already available (and where they are absent) and how they fit into the broader health or education system. Local DPOs may also be useful in determining how the research findings can be utilised to promote more inclusive practice and/or influence policy.

- **Mapping of data sources and processes:** This may include identifying and, where possible, accessing data sources that have collected information on disability, such as national or sub-national census or survey data. For example, Demographic and Health Surveys and Socio-Economic Surveys often include items to identify households or individuals with disabilities that can be used to disaggregate data on health or employment outcomes; or Education Management Information Systems (EMIS) data may help identify the number of children with disabilities enrolled in schools. Understanding how data is collected, stored, analysed, and utilised in policy and programming by different stakeholders can also help assess any gaps in the quality and usefulness of existing data systems that may be addressed through research.

The options for engaging relevant stakeholders in any of the above key areas can include:

- Working with researchers or counterparts with a lived experience of disability.
- Establishing a research advisory committee or peer review group.
- Conducting research workshops across the research cycle.
- Consulting with people with disabilities, and their representative organisations at various stages of the research.
- Engaging via online platforms and social media.

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Key Resources and Further Reading:

- Jones, H. and Wilbur, J. (2014). *Compendium of accessible WASH technologies.* WaterAid. Retrieved 10 May 2020 from https://washmatters.wateraid.org/publications/compendium-of-accessible-wash-technologies
- For more on the Washington Group questions, see **page 90**
- Sarom, M. (2017). *Going viral to promote hygiene: four tips to get a million people dancing to a handwashing song.* WaterAid. Retrieved 20 May 2020 from https://washmatters.wateraid.org/blog/going-viral-to-promote-hygiene-four-tips-to-get-a-million-people-dancing-to-a-handwashing-song
- See the W-DARE online platform for engaging with stakeholders and sharing research findings and experiences: https://wdare.wordpress.com/
- For stakeholder analysis and engagement worksheet templates
    - RDI Network (2020F). *Enhancing Research Impact in International Development: A Practical Guide for Practitioners and Researchers*. Authored by: Georgeou, N., & Hawksley, C. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2020/02/ERIID_V8_DIGITAL.pdf
- Turnhout, E., Metze, T., Wyborn, C., Klenk, N., & Louder, E. (2020). The politics of co-production: participation, power, and transformation. *Current Opinion In Environmental Sustainability*, *42*, 15-21.

Case Study F: Understanding local context and utilising existing research to embed inclusion in development projects

WaterAid provides sustainable access to clean water, toilets and good hygiene practices around the globe. To ensure that access to water, sanitation and hygiene practices (WASH) are maintained, WaterAid take a systems strengthening approach to working with local governments, civil society, rights groups and communities to identify priorities and support appropriate responses. System strengthening means understanding that WASH exists in complex systems with many component parts and within different social, economic, political and environmental contexts. It involves identifying and working to address the barriers in behaviours, policies, processes, resources, interactions and institutions that block achievement of inclusive, lasting, universal access to WASH.

This means that WaterAid works with local communities to understand the local needs, to choose the right infrastructure, and to implement a system for accountability. Without strong systems in place to turn policies into action, or to build a workforce of skilled professionals to plan, manage and maintain the infrastructure, there is a risk of poor quality water pumps and toilets which fail to be used, are neglected and fall into disrepair over time.

"It's about developing the skills of communities, governments and service providers to finance, manage and maintain services." - WaterAid website

To support local civil society, rights groups and communities adapt inclusive WASH infrastructure, WaterAid developed a compendium of options appropriate for people with disabilities and their families in rural areas of sub-Saharan Africa. This was compiled with local communities to understand local needs and help select the right infrastructure. The *Compendium of accessible WASH technologies* by Hazel Jones and Jane Wilbur (2014) states:

> "Most of the ideas are suitable for disabled and older people, but are not only for them. As we get older, many of us find it increasingly difficult to squat and balance, or we might be injured or sick. These technologies might also make facilities easier and more comfortable to use **by everyone** in the family.
>
> The compendium can be used in various ways:
>
> - As a starting point for discussion with households
> - As a way of encouraging communities to consider design options
> - By disabled people's organisations
> - As flashcards - images can be enlarged and stuck on card
> - As posters - images can be printed and used for group discussions"

The compendium then outlines general design standards and recommendations for inclusive infrastructure; often which can be simple and low-cost.

The compendium is used by WaterAid and partner staff to prompt discussion with community members to help choose appropriate infrastructure options without explicitly identifying people with disabilities.

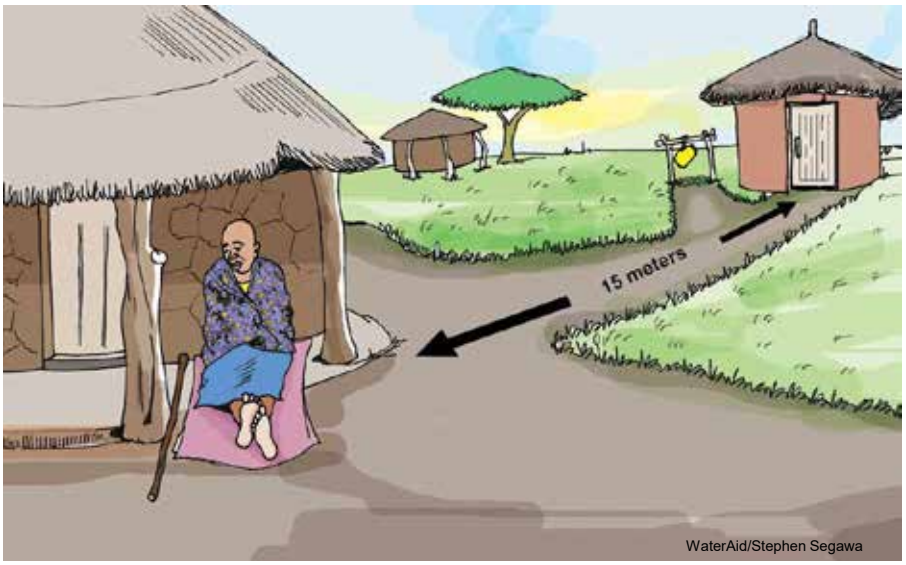
However, as part of the community engagement processes, efforts are made to identify people with disabilities using an adapted version of the **Washington Group** questions.

In doing so, WaterAid's processes embed disability-inclusion by **1)** involving the local community in design planning, **2)** utilising and sharing existing recommendations for inclusive infrastructure with local community and staff, **3)** explicitly surveying the local community to identify people with disabilities to ensure that their needs are met.

Figure 9: Excerpts from Compendium of accesssible WASH technologies

Latrines

Siting



Latrines should be no more than 15m from the household.

Waterpoints

Accessing stored water

Suitable for: children, people with limited strength, difficulty bending or lifting, poor balance, or the use of only one arm

	Construction	Advantages	Disadvantages	Improvements/ variations	Cost/ labour
	**Water stored in a bucket accessed via a tap near the bottom**	• Tap enables controlled flow and low risk of contamination • Wide opening of bucket is easy to fill	• Might not be on sale locally		Medium

Another example of understanding local context is WaterAid Cambodia's viral video on hand-washing, *'Leang Sam Ath (Wash It)'* . The music video has had over a million views online and offline.

WaterAid Cambodia paired up with Epic Arts, a local inclusive arts organsiation to develop a creative handwashing message. While the intended audience was Cambodia's general youth population, the video's message reached and influenced many outside this demographic.

Epic Arts led all aspects of the production process – including consent and choreography. The video features multiple young people with and without disabilities dancing together, miming handwashing techniques and singing lyrics specifically targetting the local context.

Such decisions - from depicting a particular type of handwashing gesture, to dance moves that everyone can perform, to relating to general public situations (eg. dancing in a club, eating lunch, buying food from a street stall etc) - would have been made together with the people participating in the video

See the video: https://www.youtube.com/watch?v=hMc75WyaqZs&list=RDhMc75WyaqZs&start_radio=1&t=1

Figure 10: Still from music video 'Leang Sam Ath'

Step 3: Planning for disability-inclusion across all stages of the research

To effectively plan for meaningful inclusion, it is important to identify the potential barriers to incorporating people with disabilities throughout the research process. This also means identifying local customs and developing locally specific solutions that do include people with disabilities.

Similarly, budgeting for inclusion is also crucial. Securing adequate funds for inclusion across all stages of the research means that reasonable accommodations can be realised, and resources can flow directly to local DPOs and local communities.

It also ensures that the labour and knowledge that local people with disabilities provide are similarly valued as international staff. The following section highlights some key considerations around reasonable accommodation and key costs that may be related to disability-inclusive research.

Reasonable Accommodation

The term **'reasonable accommodation'** or **'reasonable adjustment'** refers to specific support or modifications, requested by a person with a disability. The adjustments are required to address a specific barrier to participation so that people with disabilities can enjoy their rights on an equal basis with others. It can also apply to addressing barriers for a person who has a caregiving responsibility for a person with a disability. When a request is made to a researcher, the adjustment is required to be provided immediately.

Refusing to provide reasonable accommodation when requested constitutes as discrimination on the basis of disability.

While it would be ideal to have **all** reasonable accommodations realised immediately, the authors of this guidance acknowledge that not all adjustments can be met immediately and that they might sometimes prove to be an undue burden for the research team. However, accessibility can be progressively realised and then achieved over time.

Please see **Case Study G**.

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Reasonable accommodations can include:

- Provision of sign language interpreters (on request) to enable a deaf person to participate in a meeting.
- Provision of a report in an accessible format such as Braille or large print (on request) to enable a person with vision impairment to read.
- Ensuring that meeting times are suitable and convenient for a person with a disability, or a person with caring responsibilities for a person with disabilities (perhaps early morning meeting times make accessing transport difficult or conflict with caring responsibilities).

Note that a request does not need to include the words 'reasonable accommodation', nor must it identify a particular solution. For example, someone might ask: "Can I get this document in an accessible format?". This is still a request for reasonable accommodation and should be responded to on that basis.

Reasonable accommodation also **differs** from other efforts to promote inclusion and address barriers. While researchers should aim to ensure that research activities are as accessible as possible to people with disabilities, there may be aspects that are too difficult or too costly. Examples of this include:

Inclusive Practice	Reasonable Accommodation
All materials printed in large-type format and/or Braille	Materials printed in large-type format and/Braille on request
Researchers and project members are trained and fluent in (local) sign language	Providing a sign language interpreter on request
All audio materials are transcribed and include transcriptions online and offline	Providing transcriptions on request
All downloadable materials on a website are screen-reader accessible PDFs and alt-text is provided for all images	Providing downloadable materials in PDF and Word formats, and alt-text may or may not be included
Ensuring meeting rooms and workspaces are always spacious and accessible for wheelchair users and mobility-aids	Changing the layout of meeting rooms and workspaces on request to allow wheelchair and/or mobility-aid access
Providing quiet, breakout spaces designed to lower sensory stimulus	Providing a quiet room on request
Communicating and checking-in with people with disabilities about their needs and accommodations at regular intervals	Providing reasonable accommodations when requested; person with a disability must seek out adjustments

By making reasonable accommodations, researchers can ensure that **on request**, an individual with a disability is able to participate in research on an equal basis with others. Reasonable accommodations should be immediately realised where 'reasonable' and appropriate. Reasonable and appropriate includes where the adjustments are affordable and available. The accommodations required should not put an undue cost or burden on the agency or individuals responsible for carrying out the adjustments.

> If an action is well beyond the scope of the overall research budget, cannot be achieved in the time available, or requires technology not available in the country, it might be considered unreasonable.

However, there may be multiple ways of addressing a specific barrier. If one accommodation is unreasonable, then other ways to meet the request need to be considered.

See **Appendix 8** for tips on planning inclusive meetings.

Case study G: Example of reasonable accommodation in research

A local research partner located in a developing country has a two-storey office, which is not wheelchair accessible. Staff involved in a research project are working from this office. Rachida, a local DPO representative who is a wheelchair user, wishes to participate in steering committee meetings being carried out as part of the project. She asks that as a reasonable accommodation, the research project office be moved to an accessible building to enable her participation in the meetings.

After investigating, the project team determines that renting space in an accessible building to permanently move the project office would be very expensive. However, they discuss options with Rachida and together agree that the steering committee meetings will be held in an accessible meeting room at a nearby hotel. They also agree that they will provide a transport allowance to Rachida to support her attendance, as she cannot use public transport to reach the hotel due to lack of accessible options.

The costs of venue hire, and the transport allowance are covered by the research project's budget line for disability inclusion.

When is Reasonable Accommodation required?

Simply, when requested and it is reasonable to do so. Under the CRPD, States Parties are **required** to address specific barriers for individuals with disabilities by providing reasonable accommodation.

This means that the Australian government and its partners are obligated to both maximise accessibility within its programs and provide reasonable accommodation to those who request it unless it would be an undue burden for them to do so. This includes partner organisations involved in implementing development or humanitarian programs and activities. Researchers being funded by the Australian aid program are included. Research funded through other sources may also include a requirement for reasonable accommodation.

Irrespective of strict, legal obligations, a research team ought to provide reasonable accommodation where possible. It is ethical conduct to approach research practices with a broad and inclusive lens. Systems and processes designed to embed inclusion offer a flexible way to address the barriers to participation faced by people with disabilities on a case-by-case basis.

Practical ways to provide reasonable accommodation within research

Reasonable accommodation measures should not be a substitute for general accessibility measures. Look for ways to promote full accessibility, in addition to having a system for responding to reasonable accommodation requests.

This can be done by:

- Establishing a mechanism to:
    - **I.** Encourage requests for reasonable accommodation.
    - **II.** Ensure timely responses to such requests.
    - **III.** Ensure that DPOs and community members are aware of the above processes.
- Raising awareness of those involved in research of the obligations for reasonable accommodation and the processes developed to respond to requests.
- Seeking advice from local DPOs and service providers on ways to address specific barriers or meet specific requests.
- Looking for innovative ways to support access and address barriers. Be proactive. Even if reasonable accommodations are provided 'on request', research teams can brainstorm possible barriers and ways to address them before it is required. Researchers may discuss with individuals about their needs, as long as this is done in a sensible and respectful manner.

- Including a budget line for funds to support reasonable accommodation. The amount will differ depending on the context and the size of the research project. A project looking specifically at disability or engaging with people with disabilities might include a higher budget for disability inclusion.

Budgeting for disability inclusion within research

The cost of any research depends on many factors, including scope, geographical context, research methods, research capabilities and local costings of the research. The ideal budget includes adequate funding for appropriate resources to support inclusion of people with disabilities.

Budgeting for disability inclusion within research is equally influenced by many factors including:

- Disability-inclusion capabilities of research team and stakeholders
- Accessibility of research area/s and availability of transport
- Methodology and types of research tools and methods being used
- Provision of reasonable accommodation requirements
- Provision of participation support requirements

Research partners with lived experience of disability and knowledge of the local disability context are the best source of advice on developing a research budget. Areas with potential costs related to disability inclusion include:

- Resourcing of local partnerships with people with disabilities and their representative organisations, to enable their meaningful and active participation across all phases of the research cycle.
- Employment of people with disabilities as co-researchers. This includes resourcing any required support persons or sign language interpreters to enable researchers with disabilities to work.
- Disability awareness-raising and research capacity building workshops for research team members and stakeholders. It is essential that people with disabilities and their representative organisations are resourced to co-develop and deliver any capacity building related to disability inclusion.
- Resourcing for inclusive research tools and methods to enable participation (See **page 83** for **Case Study I**).

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- Additional time for data collection and participatory analysis, as well as resources, such as text-to-speech software that enable participation of data collectors with disabilities.
- Additional project scope to include identification and reduction of barriers to the inclusion of participants with disabilities in all aspects of the research (e.g., information about research, data collection and analysis, dissemination).
- Hiring of accessible venues for consultations, workshops and data collection.
- Provision of accessible transport and/or additional time to travel to research sites and conduct research to enable participation of staff and participants with disabilities.
- Reimbursement of any additional costs incurred by participants with disabilities that are generally reimbursed to other research participants (e.g., time, transport, meal allowance, support persons).
- Dissemination and provision of research information in a range of formats (e.g., inclusive community consultations, accessible reporting, sign language interpretation).

Budgetary consideration should also be given to the most effective way to conduct disability-inclusive qualitative research. As such, it may seem more cost-efficient to conduct focus group discussions with people with the same participation requirements (e.g., sign language interpretation, easy-to-understand methods for people with cognitive impairments).

However, this could isolate and reinforce othering of people with disabilities. It is generally recommended to include people with disabilities within mainstream research activities. Consultation with local DPOs and people with disabilities can help to identify the most appropriate option for particular groups.

Case Study H: Practical, low-cost approaches to reasonable accommodation

The Southern Africa Livelihoods Project (SALP) is a three-year project that commenced in mid-2017 and will be completed in June 2020. SALP is supported by the Australian Government through the Australian NGO Cooperation Program (ANCP). SALP worked with rural communities in Eswatini, Lesotho and South Africa to create highly productive and profitable agricultural enterprises and to alleviate poverty in some of the most vulnerable communities. Disability inclusion was strongly emphasized in the project.

Conor Ashleigh, visual storyteller and communications consultant, was engaged by World Vision Australia (WVA) to work alongside project staff and SALP project groups to understand how change arises at the individual, group and project level. As SALP drew closer to completion, Conor contributed to the final evaluation.

Using a two-part photo voting activity Conor facilitated a series of participatory workshops with 9 SALP groups to better understand their most important stories of change. This case study examines how the Photo Voting (PV) method contributed to the project's final evaluation and demonstrates a practical, low-cost approach to planning, designing and implementing inclusive and participatory activities.

What is Photo Voting?

PV comes from a broader collection of visual methodologies including photovoice, autophotography and photo elicitation. As a tool to collect data imagery/pictures are used in a variety of ways including engaging participants through the creation of images, interpreting or sequencing them, or, in this instance, voting for the pictures that best capture what change means for them.

Using images as a primary source can lead to engagement with visual imagery and thematic representation that may not necessarily emerge through other methods such as Focus Group Discussions. The use of photography to prompt personal reflection and group discussions enables communities to **1)** freely discuss their community's strengths and concerns; **2)** promotes critical dialogue about personal and community issues; and **3)** links community members to policymakers to promote change (Hannay, Dudley, Milan and Leibovitz, 2013).

To ensure this method is accessible for people with visual impairments, images could be described orally. Otherwise, recordings of soundscapes that are associated with different settings could also used.

PV was specifically selected to engage vulnerable communities including people with disabilities. Participants valued being invited to personally reflect and anonymously vote up change using photographs. This non-verbal aspect of the workshops was highly valued as demonstrated by participant feedback.

Figure 11: Winstone Hlugwane is a member of Tanani Matiko 2 in Giyani, South Africa smiles while holding a photo of himself.

"What I've seen from the photos ... you'll find those photos show the journey that we went and where we are right now. And lastly, it shows that what mostly do we do, even the activities that we did, when we were not realizing that we are still assessing ourselves, that what we are actually doing and we got it from the photos."

- Poso Maroba, Senekane Agriculture Associaton, Lesotho (2020)

Consider how communication of this participatory process can be as simple and as accessible as possible. For example pictorial and or easy read guide could be developed to ensure information is communicated in an accessible format for people with hearing and intellectual impairments.

"It was an enjoyable activity. I really enjoyed it myself, what I learned was that one needs to think wide, broaden the thinking. It was a picture but from the picture there was a lot that was coming from it, as of now I am sitting next to a poll, from this poll there is a story that I can tell so it was a good exercise, it had so much creativity."

- Bongekile Gailer, Khanyisani Manyandza, Eswatini (2020)

Approaches to Inclusion

World Vision Australia has been able to meaningful involve women, young people, and people with disabilities using photo voting to communicate stories of change. In fact, the active participation among people with disabilities has strengthened individual confidence and shifted perceptions at a broader community level.

Using a visual medium where all participants can vote anonymously creates a safe space for all. However, it is important to consult the participants to define and co-create an atmosphere and space that feels safe and supportive to all. This includes ensuring that all participants are throughly informed about PV methodology, the voting process, and subsequent discussions including how the information collected will be used.

Ensuring that all participants geniunely understand the activity may mean the use of multiple forms of communciation. See **Appendix 4** for tips on communicating with people with a variety of impairments.

Another example of a practical and low-cost approach for accomodate various disabilities was the simple use of a table to provide privacy. A table was laid on the ground sideways to ensure the photos are reachable for people in wheelchairs while still ensuring privacy when voting from others in the room. See **Figure 12**.

Consider how feedback and opinions from participants can be encouraged and embedded into practice. It is important to ensure that participants are empowered and given the choice as to how they want to be involved and what supports they may need to do so. This includes working with local community solutions to including people with disabilities.

Learnings

The PV method is an innovative approach that provides non-verbal mediums of communication. Such forms of communication can generate greater participation among people with disabilities. As a participatory approach, much thought and consideration must be taken into how the voting proccess is explained to participants, how a safe and comfortable space is provided to freely vote and discuss opinions, as well as approaches to include those who are unable to participate verbally. Consider also the trusted relationships required to work with participants who may have not yet experienced an activity where their opinion, perspective or ideas have been valued.

In this PV activity, the participatory analysis section provided a platform for community members, with and without disabilities to be meaningfully listened to by other members. Reflecting on the use of PV method, in the future it could be applied to more projects working with and without people with disabilities.

For step-by-step guide to PV, see **Appendix 9**.

"I liked it a lot although it was challenging. Upon reflection at the end you realize that it makes you change how you are thinking. The activity made us think deeply and not just look at photos as we always look at them, we always seek to understand what the photo means. So as we did the activity it was challenging but very important in the life of this project and our own lives and families."

- Musa Rasehlomeng, Senekane Agriculture Associaton, Lesotho (2020)

Figure 12: Sasavona Zitha from *Tanani Matiko 2* in South Africa points to the photos she wants to vote for and is then assisted by SALP staff member Mbeki Ndlovu to place the votes on the images. © 2020 Conor Ashleigh / World Vision Australia

Key Resources and Further Reading:

- **Appendix 8:** Six tips for planning and running inclusive meetings and events.
- **Appendix 9:** 5 Steps to Photo Voting (PV)
- A guide to conducting disability-inclusive meetings which may also be useful to consider when developing inclusive research budgets.
    - UN ESCAP. (2015). *Disability Inclusive Meetings: An Operational Guide* [PDF]. United Nations Publications. Retrieved 8 April 2020, from https://www.unescap.org/sites/default/files/Disability%20Inclusive%20Meetings%20PDF.pdf
- For more on PV and other longitudinal storytelling approaches, see https://www.conorashleigh.com/
- Women with Disabilities Australia. (2020). *Easy English Guide to Zoom Meetings* [Word Doc / PDF]. Women with Disabilities Australia. Retrieved 14 April 2020, from https://ourplace.wwda.org.au/resources/zoom-meetings
- CBM Global. (2020). *Overview on Accessibility of Video Conferencing* [Word doc]. Authored by Dr. Elizabeth Lockwood. Retrieved 27 May 2020 from http://www.internationaldisabilityalliance.org/sites/default/files/accessibility_of_video_conferencing_apps_and_services.docx

Step 4: Capacity building approaches for disability-inclusive research

To determine the type of capacity building activities required by the project team, local DPO partners and other partner organisations, you need to establish and map the cohort's existing skills and knowledge. Establishing existing skills and knowledge from the research team members and partners across the areas of disability, research, local contexts, and area of interest will identify strengths, weaknesses, and opportunities across the project group. This will then inform the capacity building activities and how both existing knowledge and capacity building activities may be incorporated across the research cycle.

Key steps to practice disability-inclusive development collaboratively:

- Identify existing skills, knowledge, and gaps.
- Design and budget for capacity building approaches and activities at key stages of the research cycle.
- Deliver and implement capacity building approaches and activities at key stages of the research cycle.
- Reflect continuously on effectiveness and lessons learnt through the capacity building approaches.
- Make required changes responding to the feedback from capacity building activities.

During this step, it is also important to again acknowledge the power differentials that exist between researchers, local community, research beneficiaries, donors, and other stakeholders.

These capacity building activities can address some of those inequalities. Consider research outputs such as research reports and academic papers. Also, what potential challenges may transpire in co-authoring with local stakeholders when certain (Western) standards are required for publishing, or when documenting local knowledge can be viewed as 'less than' academic (Teixeira da Silva, 2011).

Various research activities will have different levels of capacity building goals, requirements, and available resources. The following case study from the W-DARE project (also featured in **Planning Phase: Step 1**) demonstrates how capacity building can be embedded throughout the research cycle. The case study includes recommendations for the training of survey teams.

It has been adapted from the **Rapid Assessment of Disability (RAD) toolkit** which was developed for the W-DARE project to estimate prevalence of disability in a population. Please see **Case Study I**.

Case Study I: Building capacity of the partners - Training of Rapid Assessment of Disability (RAD) survey teams

The following example includes recommendations for the training of survey teams. It has been adapted from the RAD toolkit which was developed to estimate prevalence of disability in a population, to establish baseline information on disability among adults (18 years or over), and to support the design, implementation and evaluation of disability inclusive development projects. It was designed with a range of potential end users in mind including governments, development agencies, DPOs, NGOs, civil society organisations and research institutes.

The RAD toolkit contains a set of quantitative questionnaires and accompanying guidelines on the contents of the questionnaires and their use. The RAD survey consists of household and individual questionnaires administered by an interviewer. Each head of household is invited to complete the household questionnaire, which is designed to assess household demographics and socio-economic status. Individuals residing in the household who are 18 years of age or older are then invited to complete the individual questionnaire with the interviewer. A children's questionnaire has also been developed.

The individual questionnaire consists of four sections:

- **Section one**: Demographics
- **Section two:** Self-assessment of functioning
- **Section three:** Well-being
- **Section four:** Access to the community.

While the RAD has been designed as a stand-alone survey, programs may choose to only use specific components of the RAD, i.e. if a program is focused on WASH, it may choose to only use items from **Section four** which are relevant to WASH and use the format in that section to develop new questions specific to collecting data on access and barriers relevant to the program.

Length of training

The length of training will depend on the type of RAD survey being implemented and the skills and experience of the local survey teams, but it should be at least one week. It may not be necessary for all survey team members to attend all days of the training; this will depend on the RAD survey being implemented.

Suggested content of training:

- Overview of disability: global and local perspectives
- Disability-inclusive development
- Rights-based approach to disability-inclusive development
- Introduction to the RAD survey
- How the RAD survey will be implemented
- Study design
- Getting to know the RAD household questionnaire
- Getting to know the RAD individual questionnaire (18 years or older)
- Ethics in research and collecting survey data
- How to be a good interviewer
- Practice exercises (in pairs, small groups, role plays)
- Interviewing people with a disability – techniques and tips
- Mapping and sampling
- Recruitment of participants
- Matching controls
- Data storage
- Referral process for participants identified as having a disability or requiring support
- Pre-testing and supervised practise in the field.

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Key Resources and Further Reading:

- For further information or to request a copy of the RAD manual, please contact the Nossal Institute for Global Health (RAD-enquiries@unimelb.edu.au).
- Templates for group development, skills audit, and capacity audit.
    - Wright, N. *Group Capacity Building* [PDF] (pp. 15-20). Volunteering Queensland. Retrieved 8 April 2020, from https://volunteeringqld.org.au/docs/Leadership_Group_Capacity_Building_Tool.pdf

Design Phase

The design phase of the research cycle is a concrete example of how disability-inclusion within research is both a process and an outcome. This means that people with disabilities can participate fully in the research process *and* experience the benefits of research outcomes on an equal basis with people without disabilities (Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, 2015).

Considerations will need to be given for encouraging and including **1)** participation of co-researchers and team members with disabilities, and **2)** participation of individuals with disabilities, their support people and/or people with caring responsibilities for people with disabilities.

Ensure that the research process is adaptable enough to engage stakeholders in a meaningful way as an ongoing process at all phases of the research. This is equally true for projects that specifically focus on disability as for those that do not.

The most collaborative approach to this is to engage with local DPOs and partner organisations in the **co-production** of research. The involvement of the disability community must be also undertaken with due recognition of **intersectionality**. That is, recognising that the experiences of people with disabilities will vary widely according to factors including gender, sexuality, age, class, and income status, as well as their various impairments.

"Adopting co-production as a principle of research represents a significant shift of power from the researchers or the funders to the research users.

Co-production involves the collaborative creation of research outcomes with local partners."

- (RDI Network, 2020, p. 25)

In the designing of disability-inclusive research projects, consider utilising:

- **Do no harm approach:** utilise a do no harm approach that pro-actively seeks to reduce harm to people with disabilities involved throughout the research cycle.
- **Participatory action research approach:** utilise a participatory action research approach that actively seeks to ensure collective inquiry and empowers people with disabilities.
- **Strengths-based approach:** utilise a strengths-based approach that recognises the contribution of people with disabilities to research and builds on their existing strengths.

Developing research questions

In partnership with local DPOs, the study team will need to consider the priorities and agendas of all stakeholders involved. This includes understanding how the focus of the study may relate to people with disabilities; what are their needs and priorities in relation to the focus of the study; and what factors influence their inclusion or exclusion in relation to the area of focus.

This collaborative process then enables all partners to shape the research objectives and develop a sense of shared ownership for the research. In working with a diverse team, the diversity of experiences and abilities will instinctively support the development of appropriate and inclusive methods. This includes consciously identifying barriers to include people with disabilities, as well as identifying locally developed solutions that can be incorporated into the methodology and the budget.

Methodological approaches

Depending on the aim of the research, the study population and the availability of resources, research teams may decide to use quantitative or qualitative approaches, or a combination of both. **Quantitative techniques** collect numerical data through experiments, polls, questionnaires, or surveys and use statistical methods to determine facts and figures. **Qualitative techniques** include interviews, focus group discussions, community consultations and participatory techniques to understand in more depth people's subjective perspectives, contextual conditions, and experiences. Depending on the nature of the research questions and objectives, it may be that both techniques are used to understand a situation. Mixed methods research involves collecting, analysing and integrating quantitative and qualitative data.

Whatever methods are used, research teams need to ensure research methods and tools are accessible to people with a variety of impairments. This includes determining the most appropriate language to use to elicit information from participants, particularly when eliciting sensitive information on abilities and functioning.

See **Case Study J**.

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Utilising participatory techniques designed for people with disabilities shapes the methodological approach to be tacitly inclusive.

See **Appendix 10** for the CBM-Nossal Plan practice note on participatory techniques.

The participation of women, men, girls, and boys with disabilities in designing, adapting and implementing data collection and analysis methods is a key principle of disability-inclusive practice.

Case Study J: Inclusive methodological approaches to include people with disabilities - Exploring the lived experience of people with psychosocial disability in Afghanistan, India and Nepal utilising participatory research methods

In 2015, TEAR Australia embarked upon a research journey to learn from its partners about psychosocial disability and development in three contexts: Afghanistan, India and Nepal. In addition, it was hoped that the research would strengthen inclusion and utilise lived experience perspectives into program planning.

Approaches to Inclusion

To honour the commitment to equitable partnership, a participatory action research (PAR) approach was employed. PAR methodologies strongly encourage significant collaboration and learning between all stakeholders and give space to involve people with lived experience within their socio-cultural contexts.

Tools and Methodology

To remain true to principles of PAR methodologies, people with lived experience of psychosocial disability, families, communities and TEAR's partners were involved in agenda setting for the research. A small research reference group was also formed to guide the research design, research process and decision making, and to expand sharing of the learning and knowledge translation across networks. The research reference group was formed through TEAR Australia's networks, and, more importantly, it collectively encompassed those with experience in inclusion, development and lived experience of psychosocial disability.

This group was instrumental in challenging and supporting TEAR's research team throughout the research process. The group identified that:

- Evidence of inclusion of people with psychosocial disability in LMICs was limited and scarce.
- Little was known about the actual experience of people living with psychosocial disability in LMICs.

The reference group strongly encouraged TEAR to obtain ethics approval, so that the learning would be achieved in a robust way. It also meant that the learnings could be shared with broader networks with enhanced credibility. The group worked collaboratively with TEAR's implementing partners to also further refine the research questions.

Additionally, the formation of an inclusive research reference group strengthened accountability in multiple ways. This included:

- Supporting the researchers to ensure that principles of participatory research were followed.
- Promoting the involvement of people with psychosocial disability as research assistants and co-researchers.
- Supporting TEAR to increase scientific rigor through an academic partnership with the Nossal Institute for Global Health.
- Building capacity of co-researchers and research assistants throughout the research process.
- Supporting co-researchers and research assistants to translate the findings of the research to strengthen their inclusive practice.
- Time was spent developing comprehensive training manuals, which utilised visual learning tools, were simple to translate and broke down the research into smaller planning tasks. These tools were used during the formal training sessions with all relevant staff and volunteers.

Learnings

In itself, the research process was a significant opportunity for everyone involved to learn from each other. Through the involvement of people with lived experience as research assistants and participants, they were able to highlight their experiences and showcase having agency. Other partners and team members were able to practice inclusion in a concrete and tangible way. This promoted an increased understanding about psychosocial disability and about inclusive practices.

However, TEAR did find it challenging to engage the reference group meaningfully during every phase of the research. To address that, TEAR adopted a mixture of platforms in which to proactively seek input and communicate progress.

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Key Resources and Further Reading:

- **Appendix 10:** CBM-Nossal Plan practice note. Table 2 - Collecting and using information about disability throughout the project cycle
- Humanity & Inclusion (Operations Division) and F3E. (2018). *Incorporating the principle of "Do No Harm": How to take action without causing harm. Reflections on a review of Humanity & Inclusion's practices.* Authored by Jean Martial Bonis Charnacle and Elena Lucchi [PDF]. Retrieved 6 May 2020, from https://www.alnap.org/system/files/content/resource/files/main/donoharm_pe07_synthesis.pdf
- Chevalier, Jacques M. and Buckles, Daniel J. (2013) *Handbook for Participatory Action Research, Planning and Evaluation, SAS2 Dialogue, Ottawa.* Retrieved 6 May 2020, from: http://www.participatoryactionresearch.net/sites/default/files/sites/all/files/manager/Toolkit_En_March7_2013-S.pdf
- Positive Psychology (2020). *What is a Strength-Based Approach?* Authored by Erick Stoerkel, MSc [Webpage]. Retrieved 6 May 2020, from https://positivepsychology.com/strengths-based-interventions/
- Allan, E.B., Najm, A.F., Fernandes, H., & Allchin. B. (2018). *Participatory lived experience research: Barriers and enablers for social inclusion for people with psychosocial disability in Afghanistan.* Intervention, 16(3), 222-230.
- Fernandes HL, Cantrill S, Shrestha RL, Raj RB, Allchin B, Kamal R, et al. *Lived experience of psychosocial disability and social inclusion: a participatory Photovoice study in rural India and Nepal*. Disabil CBR Inclusive Dev. 2018; 29(2):5–23.

Enabling disaggregation of data by disability

Disaggregation of data is the process of dividing data into subgroups and comparing data from each of these subgroups. Data may be disaggregated by gender, age or socio-economic status. Disaggregation by disability requires identifying people with disabilities within existing surveys or other data collection methods. When data is disaggregated, it allows researchers to investigate:

- Whether different groups of people with disabilities experience and participate in various aspects of community (e.g., school enrolment, access to a program) differently; and, if so,
- How different groups experience and participate in various aspects of community (e.g., school enrolment, access to a program) differently.

If disaggregation of data by disability is required, it is important to establish which methods will be used to collect data and how they will be analysed.

The **Washington Group (WG) on Disability Statistics** has developed a number of tools to support the measurement and disaggregation of data on disabilities. These include:

- The **WG Short Set of Questions**: designed to identify people at greater risk than the general population for participation restrictions due to difficulties across six core domains. See **Appendix 11**.
- The **WG Extended Set of Questions**: designed to assess the above six domains, as well as additional domains in:
    - Functioning and its affects (anxiety, depression, pain, fatigue etc);
    - Functioning with and without the use of devices/aids; and
    - Age of onset and other environmental factors that may influence functioning and/or participation.
- The **WG/UNICEF Module on Child Functioning**: designed to be use for children between 2 and 17 years.

The main benefit of the **WG questions** is that they focus on functioning and do not require people to self-identify as having a disability.

Requiring people to self-identify as having a disability has been shown to be less effective at identifying people that may benefit from reasonable accommodation. The WG questions can be included within household surveys, program administration forms, censuses or other population-based surveys (e.g., the RAD incorporates the WG questions). The WG questions can also be a part of collecting demographics from participants within qualitative research.

Key Resources and Further Reading:

- **Appendix 11:** Washington Group Short Set of Questions
- For more information and access to the WG questions, refer to**:** http://www.washingtongroup-disability.com/
- For more examples of reasonable accommodations to consider:
    - Australian Human Rights Commission. (2016). *Access for all: Improving accessibility for consumers with disability* [PDF]. Australian Human Rights Commission. Retrieved 8 April 2020, from https://www.humanrights.gov.au/our-work/disability-rights/publications/access-all-improving-accessibility-consumers-disability
- Council for Intellectual Disability. *Inclusion High5*. Council for Intellectual Disability. Retrieved 8 April 2020, from https://cid.org.au/resource/inclusion-high5/
- For more information on TEAR Australia's research on lived experience of psychosocial disability in Afghanistan, India and Nepal.
    - TEAR Australia. (2017). *Photovoice study on inclusion of people with psychosocial disability in rural India and Nepal: Final Report* [PDF]. TEAR Australia. Retrieved 8 April 2020, from https://assets.tear.org.au/files/TEAR_Resource_Photovoice_Community-Inclusion-for-Mental-Health_2018_n1.pdf

Implementation Phase

In the implementation phase, research teams can **explicitly** demonstrate disability-inclusive practice and promote the capacity of people with disabilities and their representative organisations.

Methods of conducting research need to ensure that data collection activities respect the contributions of people with disabilities. This means supporting people with disabilities and their representative organisations to meaningfully engage in the research, while also meeting the research objectives.

In practice, both design and implementation phases should actively seek to ensure the meaningful involvement of people with disabilities. This includes:

- Ensuring that all data collection methods are fully accessible to people with disabilities. This will assist in the collection of quality data by reducing any bias that may occur if an important group were unable to take part (Farmer & Macleod, 2011).
- Securing equal reward for participation in research by researchers with or without disabilities (Disability Human Rights Research Network [DHRRN], 2018).
- Delivering all aspects of the research process in an accessible manner, including utilising accessible research venues and equipment, as well as easy-read materials and results (DHRRN, 2018).

Sampling

Sampling refers to the process of selecting a specified number of participants from all the potential participants in a particular group, community or population. Participants may be:

- Randomly sampled: People selected randomly from a computer-generated list of all people living in a certain area or accessing a certain program; or
- Non-randomly sampled. Non-random sampling may involve:
    - **Convenience sampling,** where the sample is drawn from a population that is known or close by, such as surveying people with disabilities from a list provided by a DPO or disability service.
    - **Purposive sampling,** which targets a particular group of people considered to be key knowledge holders (e.g., key informant interviews) or people within a group that may be difficult to find (e.g., people with particular kinds of impairment that are not so visible in the community).

- **Key informant methods,** where community leaders, DPO staff and community members with disabilities specifically identify people to be interviewed using their knowledge of a certain community or population group.
- **Snowballing** where people identified as key informants then go on to identify other people within the population group that are relevant to the research. This is particularly useful in contexts where people with disabilities may be less visible in the community.

The method of sampling is chosen based on who the research team may think will be appropriate for the study. Ensure adequate time is available to engage with the community about the research, including addressing any ethical considerations of the methods. In particular, to ensure any snowballing technique is conducted in a way that does not breech the privacy of community members and their families.

See **Appendix 12** for CBM-Nossal Plan practice note for an overview of methods and tools for collecting data to support disability inclusion.

Data collection and analysis

Applying the principles of disability-inclusive development practice to data collection and analysis requires collection of data on the specific situation of people with disabilities, *and* the inclusion of people with disabilities in the data collection and analysis processes.

Involving people with disabilities in data collection and analysis can:

- Provide positive role models and raise awareness about disability in the community.
- Challenge negative stereotypes about capabilities, and encourage more people with disabilities to participate.
- Serve as an entry point for broader disability inclusion strategies.
- Result in data collection that is more relevant and higher quality.

Proactive engagement with local DPOs and people with disabilities can result in positive change in the form of improved outcomes. In fact, during 2014-2018, CBM Australia collaborated with World Vision and WaterAid to support disability-inclusion in several 'mainstream' WASH projects, and found that the involvement of people with disabilities in data collection teams:

- Led to increased confidence of people with disabilities.
- Had immediate outcomes in relation to challenging negative attitudes in communities.
- Resulted in new forms of collaboration between DPOs, NGOs and governments, which helped to change their attitudes and approaches towards people with disabilities and to acknowledge their capacities.
- Increased the quality of data collected by encouraging community members with disabilities to speak up during focus groups and community meetings, which improved interpretation of the findings.

Practical ways to make data collection and analysis processes disability-inclusive

In addition to involving people with disabilities and their representative organisations as active advisors and reference groups, it is important to keep in mind that people with disabilities are not a homogenous group.

Some of the views and experiences of people with different types of impairment may not be represented by *only* utilising reference groups. Ensuring that people with disabilities can engage in data collection and analysis may require extra training to build the capacity of the DPOs but will ensure that the data represents a large cross-section of the demographic.

Provisions for the participation of people with disabilities and the use of inclusive data collection methods can be incorporated into research designs or terms of reference for evaluations, surveys or other processes that involve data collection and analysis. It is also pertinent to consider the following key areas to ensure accessible data collection and analysis processes.

Raise disability awareness amongst program staff and other stakeholders

Addressing attitudes and assumptions about disability and raising awareness about disability inclusion and human rights among those involved in research is an important first step towards creating an environment that enables disability-inclusive development.

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The ability of programs to collect data effectively and respectfully is dependent on team members having positive and sensitive attitudes and behaviours towards people with disabilities.

Involving research team members in inclusive activities is a key approach to challenging misconceptions about disability. The involvement of people with disabilities in the design and delivery of awareness-raising or research training activities is integral to this.

Adapting data collection methods

Irrespective of the method selected to collect data, it is imperative that interviews or discussions utilise accessible locations and appropriate communication methods. It is also necessary to assess whether people with disabilities feel comfortable and welcomed to participate. This may involve:

- Adapting the format (for example, by using written communication and ensuring people speak clearly and slowly).
- Ensuring that a protocol for verbal consent to participation is provided (not just written consent).
- Being flexible about conducting separate interviews with people who find it difficult to participate in group discussions.
- Holding separate group data collection processes for men, women, girls and boys with disabilities (as well as those without disabilities) can also help draw out different opinions and experiences of disability, which might not otherwise be mentioned in mixed groups.

At the same time, it is important that any 'whole of community' approaches include people with and without disabilities at the outset so as not to reinforce the notion of separateness or difference (othering).

Local DPOs or individuals with disabilities can advise on appropriate approaches or may be able to participate as facilitators or interpreters. Many DPOs also run self-help groups, which can be a valuable source of data when seeking the perspectives of people with disabilities. Discussions can involve people with disabilities themselves and other key stakeholders (rights holders, duty bearers, civil society and project staff) to learn more about the local disability context.

Caution is required where carers (including service providers) or family members are supporting participation of people with disabilities in data collection.

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People who require interpreters or other support in communication may not be able to provide information freely or safely in the presence of family members. This includes people who are Deaf or hard of hearing, and those with communication difficulties related to intellectual or psychosocial impairments.

In cases where research considers particularly sensitive subjects like experiences of abuse or violence, protocols must protect such participants from harm. For more on informed consent, see **page 44** of this guide.

This also applies in a broader context. Questions exploring issues such as participation, involvement in decision-making or income, should be considered sensitive information. Analysis of above issues requires exploring the power relations of decision-making processes between family, community members, and people with disabilities. The impact of drawing out such information from people with disabilities needs to be carefully considered.

All attempts made to collect such information must be gathered in a safe environment that is free from the influence of family, service providers or other community members. Risk of repercussions needs to be assessed.

It is also important to acknowledge that while there is a risk of the influence of family, sometimes the opposite is true – if family are involved appropriately, participants can feel safer and share more of their experience.

Adapting Data Analysis Methods

Quantitative and qualitative data analysis generally requires an understanding and some sort of experience of the various analysis techniques. In particular, quantitative analysis often requires statistical knowledge and skills in using statistical software (e.g., Excel, SPSS, SAS, STATA). Depending on the context and data analysis required, people with disabilities who are involved in the research may have the skills and the interest to take an active role in the data analysis. This may not always be possible, which is why alternative methods to supporting inclusion within the analysis phase will need to be considered.

Building in resources to enable participatory data analysis and capacity building processes will also be valuable to the research team members and the research. Alongside developing capacity, this will enable people with disabilities to contextualize the findings, support interpretation and further refine ongoing analysis. There are different suggestions of how this may be achieved:

- Capacity building workshops to share knowledge and skills on different data analysis techniques relevant to the research.

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- Pairing an experienced data analysis team member with one that has no or limited experience to develop their capacity to co-analyse the data.
- Graphically/visually representing the data (e.g., pie charts, infographics) to enable participatory discussion of more complex data.
- Co-analysing smaller sections of data or vignettes of the data to scaffold processes of reading sections of transcripts, and to identify key words and sentences to help determine emerging themes and how they may be interpreted.
- Conducting participatory sessions with people with disabilities and other stakeholders to share and discuss analysis processes and preliminary findings (Tuffrey-Wijne & Butler, 2009; Kramer et al., 2010).

People with disabilities and DPOs are best placed to provide their interest level in participating in data collection and analysis. Seek advice from local DPOs and service providers to understand the specific barriers that prevent people with disabilities from participating.

Work with people with disabilities to develop data collection and data analysis processes to overcome those barriers and compensate them appropriately for their services. See **Case Study K**.

Nonetheless, keep in mind that their expertise should complement, rather than substitute, seeking specific technical input on disability-inclusive data collection and analysis.

Case Study K: Inclusive approaches to data collection for people with disabilities in Papua New Guinea.

Roads link communities, facilitate transport of goods and services, enable food security and service delivery. However, while people with disabilities make up about 15 per cent of the population in Papua New Guinea (PNG), people with disabilities were rarely (if ever) consulted about their needs in determining road infrastructure.

Travelling Together: Improving access for people with disabilities through inclusive infrastructure development in rural and urban PNG sought to change that narrative. It was a three-year research project funded through an Australian Development Research Award (ADRA) that examined the integration of people with disabilities in road planning. It was implemented in 2010-2013 in partnership with the PNG Assembly of Disabled Persons (PNGADP); the Faculty of Architecture, Building and Planning at the University of Melbourne; the CBM Australia–Nossal Institute Partnership for Disability-inclusive Development; and Cardno Emerging Markets, a company involved in several PNG road projects.

Travelling Together shows the benefits of disability-inclusive development by:

- Providing guidelines to road planners on how to effectively include people with disabilities.
- Assisting people with disabilities and DPOs to use the research findings for advocacy work.
- The research had an **explicit** focus on disability and sought to answer four key questions:
    - What are the barriers and facilitators for people with disabilities accessing roads in rural and urban PNG?
    - What are the outcomes of rural and urban road projects on the lives of people with disabilities and their families?
    - How have people with disabilities participated in rural and urban road planning?
    - What are the recommended approaches in disability-inclusive consultation and participation in road planning and development in PNG?

In addressing the four key questions, the researchers looked at **positive** and **negative impacts** of roads on the lives of people with disabilities, and **how** they are currently involved in road and transport planning.

Approaches to Inclusion

As a key principle, the research team maximised the participation of people with disabilities at all stages of the research. Using a **participatory research design**, the research team involved a wide range of community members and partner organisations, including the national DPO; the PNG Assembly of Disabled Persons (PNGADP).

A PNG Advisory Committee and an International Advisory Committee, both of whom included people with disabilities, was established to advise and guide the project at a high level. People with disabilities were also central to the design of the project, data collection and analysis. Inclusive methods for data collection were developed, including illustrated posters and 'Moveabouts', an inclusive approach for people without disabilities to experiencing road usage as people with disabilities.

The project explicitly sought to build the capacity of local people with disabilities, both men and women, in order to promote ownership of the project. This included the PNG Research Officer, herself a person with a disability, overseeing the project implementation within PNG.

Tools and Methodology Used

The project used participatory methodology to conduct qualitative research in five locations where roads had either recently been built or upgraded or were currently under improvement. In each of the places, two local people with disabilities were recruited by the Research Officer as data collectors – one male and one female.

The data collectors participated in two weeks of training on the use of the four selected qualitative data collection tools, which were developed in consultation with the project's PNG Advisory Group. These were:

- Interviews with road decision-makers about processes for planning and implementing road construction or improvement, and their knowledge of use of roads by people with disabilities.
- Group discussions with groups of 7-12 people with disabilities in each location, exploring how they used roads, and documenting on the particular barriers and facilitators to accessing and using roads.
- 'Moveabouts', in which the groups selected and moved along a small segment of the road and identified specific issues regarding access and road use.
- Photo- and poster-making: group members took photos of good and bad aspects of the road and associated infrastructure, and then made posters identifying these issues.

In addition to training on the research methods, data collectors were involved in a six-day data analysis workshop, ensuring their participation was not limited to gathering information but that it also encompassed interpreting and analysing findings. This helped to build the capacity of PNGADP and the data collectors to be involved in or initiate future research activities.

The use of a range of data collection tools helped to encourage meaningful participation by all research participants. For instance, the photo elicitation allowed each participant to highlight their own likes and dislikes individually: for some this acted as a prompt and helped them to better recognise and articulate issues. The poster-making also helped to elicit responses from those who found participation in focus groups difficult – some people with speech and/or hearing impairments gave their perspectives by writing captions on photos. The 'Moveabouts' also proved important in gathering information, as most participants found it easier to discuss road usage in a real-life setting.

Research Impact and Advocacy

Including people with disabilities as data collectors and co-researchers also assisted with the advocacy impact of the project, particularly in influencing decision-makers. The data collectors reported that the very process of meeting with road decision-makers helped to change the perspectives of those they met about people with disabilities and about disability itself. During interviews, decision-makers initially displayed an understanding of disability as a health issue, but they quickly developed an appreciation that it was also a key development issue and relevant to road infrastructure. In some cases, the meetings themselves also helped to highlight accessibility issues, as sometimes the data collectors were unable to access a decision-maker's office due to steps or other access barriers.

Another key aim of the project was to contribute to the evidence-base around disability-inclusive infrastructure development and road usage in PNG. The findings were then also developed into tools and resources to promote disability-inclusive consultation processes, and planning and implementation of (future) road infrastructure. In doing so, the project provided advocacy training for DPO members. PNGADP then developed advocacy strategies on accessibility at both the provincial and national levels.

Learnings

By ensuring people with disabilities were a key part of the research cycle, DPOs were able to utilise the research findings to conduct advocacy on their own priorities and concerns. This shows that the project had shared ownership and relevance to people with disabilities and DPOs, rather than just benefiting more traditional research institutions and reaching a largely academic audience.

It is unlikely that the depth and richness of findings would have been achieved had the data collection and analysis been carried out by outside researchers. Including people with disabilities, who were also members of the communities under study, allowed the research to capture diverse viewpoints, new ways of thinking, as well as unearth 'blind spots' and hidden biases.

The involvement of PNGADP as a partner throughout the research also meant that the focus of the project was on issues of relevance to PNGADP and its members at both the national and local level.

Figure 13: Photo of the data collectors and researchers from 'Travelling Together'.

Image courtesy of CBM Australia-Nossal Institute Partnership © 2013

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Key Resources and Further Reading:

- See **Appendix 12**: Table 3: Overview of methods and tools for collecting data to support disability inclusion
- Plan International Australia, & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development. (2015). *Practice note: Collecting and using data on disability to inform inclusive development* [PDF]. Retrieved 8 April 2020, from https://www.cbmuk.org.uk/wp-content/uploads/2016/05/plan-cbm-nossal_disability-data-collection-practice-note_july2015_1607.pdf

Dissemination Phase

Research is an important contribution to knowledge. Research informs evidence-based practice, effective and ethical actions, and establishes rationale for programming and policy choices. Therefore, **how** research findings are published and broadcasted to partner organisations, local communities and the wider research community is pertinent to disability-inclusive development. Furthermore, if working with local partners and DPOs, there is an additional advantage of local backing. The research will have both (local) legitimacy and a ready-made outlet for later dissemination.

In disability-inclusive development, it is essential to ensure that communicating with the wider community is inclusive of, and accessible to, people with disabilities. Inclusive communication provides another opportunity to **explicitly** support positive change for people with disabilities. Inclusive communication reassures people with disabilities that they are considered part of the community, are positively represented, and have equal access to research.

Research teams intending to communicate the research publicly should engage with local DPOs and disability-inclusive communication specialists to appropriately disseminate plans and outputs.

This includes suitable approaches to sharing information with people with and without disabilities, as well as policies and processes to ensuring ethical use of any imagery and/or descriptions of people with disabilities. It is important to avoid (even if unintentionally) perpetuating any harmful stereotypes and assumptions.

Preparation of research products

Research products refer to materials and/or forms of communication that share the findings, conclusions and recommendations arising from any particular research. These can include:

- Journal articles
- Meetings and verbal briefings
- Websites and blogs
- Opinion pieces and commentary
- Podcasts and social media campaigns
- Policy briefs, evidence summaries and working papers
- Launches, art exhibitions, and posters
- Workshops, toolkits, and other forms of training
- Conferences, presentations, and education events

Research products, including from non-disability specific research, need to be fully accessible to people with disabilities. The preparation of disability-inclusive research products should be based on the premise that people use a variety of ways to communicate and receive information.

This includes all forms of communication, both verbal and non-verbal. Especially as non-verbal communication is often just as important as what is being verbally shared. In practice, this may require additional resourcing, including technical expertise and DPO engagement, to provide advice on appropriate formats of research products.

Being aware and actively considering the needs of people with disabilities in the preparation of research products will contribute to the development and distribution of accessible research products as a standard in the sector.

Outlined below are some practical tips to consider during preparation of research products.

Consult or partner with people with disabilities and/or DPOs

People with disabilities and/or DPOs can provide information on the current barriers to accessing research products and outputs. For example, some text-to-speech readers will only read from Microsoft Word documents, while PDFs are only readable by text-to-speech readers if formatted (coded) correctly.

People with disabilities and their representative organisations can support the development of accessible outputs by being:

- Co-producers of research products
- Co-writers in research reports, academic papers, policy briefs, etc.
- Co-presenters in conferences, workshops, videos, etc.

Consult with appropriate disability service providers

Disability-service providers can share information on expertise and various accessible practices for information-sharing. Some disability-service providers also facilitate services that could assist with developing disability-inclusive research products. This can include translation services for Braille, easy-to-read English, or local languages.

Allocate adequate funds to cater for reasonable accommodation support

The preparation of disability-inclusive research products may require additional costs, particularly the provision of research products in appropriate formats. It may also include capacity development support for people with disabilities to participate in preparation of research products.

Consultation with people with disabilities and/or DPOs, including disability service providers, during the design phase should provide an indication of costs involved for developing accessible outputs and products.

Consider co-authorship

Researchers should consider how the principles of inclusion can be carried through to the dissemination of research. Where possible, all researchers (including co-researchers with disabilities) who have played a significant role in research design, data collection and analysis should be included as authors on publications (Smith-Merry, 2017). Co-researchers with disabilities can be encouraged and supported to present the research findings at public forums and conferences. This, again, may need budgetary considerations.

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It is also important to support co-researchers with disabilities to participate in expert consultations. This can lend credibility to the disability-inclusive research and contribute new voices beyond the usual stakeholders engaging with policy makers (Farmer & Macleod, 2011).

Ensuring the accessibility of information

Inaccessible information contributes to the knowledge gap and the unequal power dynamics between researchers, local community, research beneficiaries, donors, and other stakeholders.

Information can be inaccessible when there is only one format or method of gaining reliable data ("What makes," 2020). For example, when information is only available in a written format, locked away behind a 'paywall', composed in complex terminology and jargon, or covered in only one language. Information that solely exists either online or offline may also be an impediment to accessibility and wide-spread dissemination.

Figure 14: Photo of an advocacy workshop from 'Travelling Together'

Image courtesy of CBM Australia-Nossal Institute Partnership © 2013

To ensure the general accessibility of your work, consider the following:

- All research products are spoken and written in clear English (or the language the product is developed in). Keep the language straightforward and appropriate to the audience. Avoid initials and acronyms where these become confusing.
- Produce alternative formats to address access requirements for specific groups. Through DPO consultations, you can identify disability inclusion requirements to guide preparation of appropriate alternative formats.
- Publish academic articles in open-access online journals as many DPOs, service providers and advocacy organisations do not have access to research published behind a 'paywall'.
- Develop non-traditional research products to increase the accessibility of your findings to a range of audiences. Go beyond academic publications and conference presentations, and consider blogposts, infographics or other visualisations, animations or videos, media articles, policy briefs, guidelines and toolkits, or even exhibitions or performances.

Timing dissemination activities with other windows of opportunity to connect with key audiences may also help in reaching a wider network. Communication and engagement plans can include launching toolkits at conferences, releasing media releases aligned with key days/weeks (e.g., International Day of People with Disability), holding workshops at events, or even policy briefings released during government consultations ("Autism CRC," n.d.).

There may not be a need to produce every research product in all formats, but stakeholders should be consulted and the demand for these products should be monitored in case other formats are needed (Farmer & Macleod, 2011). The most common formats to consider are:

- Large print (18 point minimum) and high contrast in text and pictures in written communication
- Accessible electronic version that can be read using screen-reader software (note that PDFs are not usually accessible for screen reader software unless specific accessibility guidelines are followed)
- Easy-read-versions, which concentrate on the main points of a document, with images, pictures, or diagrams to help illustrate key points where necessary
- Braille version – many vision impaired people now commonly use screen readers, so check which is most useful in the context
- Audio (MP3 or computer file)

- Video file with captioning or sign language
- Different colour contrasts (e.g., dark blue text on pale yellow paper)
- Appropriate visual prompts for pictures, symbols and imagery also known as **alt-text** in documents and digital content

Most importantly, **be flexible**. If one communication strategy does not work, try another. See **Appendix 3**, for tips on communicating with people who have specific impairments.

Case Study L: Why do some websites make both a Microsoft Word document and a PDF available for download?

On some websites, two types of a document are uploaded. A slick PDF version with pretty design elements, and a basic Word document with no bells and whistles. This is done to accomodate people that use screen readers to read documents.

Most generic PDFs are unreadable by screen readers, so a Word document is uploaded as a screen-reader compatible-version. This can be problematic for inclusion in a few different ways; **1)** often only a PDF is available for download, **2)** an incompatible (non-interactive) PDF excludes all those that require a screen reader, and **3)** two separate document uploads differentiates between those that use a screen readers and those that do not (othering).

It is a similiar challenge to addressing reasonable accommodation, and delivering inclusive practices.

For an accessible PDF, documents need to be deliberately and consciously designed as an **interactive PDF**. This may require the use of Microsoft Word and Adobe Acrobat Pro. Those that do not have access to Acrobat Pro can still use Microsoft Word to create accessible PDFs.

Once content is finalised, steps need to be taken to map the headings, add alternative text descriptors (alt-text) to all graphics, images and photos, and embed all hyperlinks into the display text. This document can then be exported as an accessible PDF.

Bookmarks and anchor points also need to be added. Bookmarks and anchor points are features that allow a person to click a certain word or phrase, for example, *'See Appendix 5'*, and the document will automatically jump to that page. In very large documents, this allows readers to 'jump' and 'flick' between pages, sections, resources and references.

Also, all tables within the document need to be checked so that they are read the right way in its original language (in English, that would be left to right).

Most of the common office programs (Microsoft Word, Microsoft Powerpoint, Google Docs etc) do have an in-built accessibility checker that will highlight inacessible sections, and offer reccomendations to fix.

This does not need any budgetary considerations. However, it does require additional planning time to achieve. See **Key Resources and Further Reading** for tips to ensure your next PDF document is accessible to all.

Key Resources and Further Reading:

- **Guidelines for accessibility (digital and non-digital content):**
  - CBM. (n.d). *CBM Digital Accessibility Toolkit* [PDF]. CBM. Retrieved 27 May 2020 from https://www.cbm.org/fileadmin/user_upload/Publications/CBM-Digital-Accessibility-Toolkit.pdf
  - Centre for Accessibility. (n.d). *How do I check if my work is accessible?* [Website]. Centre for Accessibility. Retrieved 15 April 2020 from https://www.accessibility.org.au/resources/how-do-i-check-if-my-work-is-accessible/
  - University of Washington. (2020). *Creating Accessible Documents* [Website]. University of Washington. Retrieved 15 April 2020 from https://www.washington.edu/accessibility/documents/
  - See Vision Australia (https://www.visionaustralia.org/) for translation services, print-accessibility and digital-accessibility training

- **Check accessibility of Microsoft Word or Excel documents:**
  - Microsoft. (2020). Make your Word documents accessible to people with disabilities [Website]. Microsoft. Retrieved 15 April 2020 from https://support.office.com/en-us/article/make-your-word-documents-accessible-to-people-with-disabilities-d9bf3683-87ac-47ea-b91a-78dcacb3c66d
  - Penn State. (2019). *Accessibility Checker for Microsoft Office* [Website]. Accessibility and Usability at Penn State. Retrieved 15 April 2020 from https://accessibility.psu.edu/microsoftoffice/checker/

- **Check accessibility of PDFs:**
  - IPDEDIS. (2016). *PDF Accessibility for the blind and visually impaired* [Website]. PDF Accessible. Retrieved 15 April 2020 from https://www.pdfaccessible.com/en/pdf-accessibility/blind-visually-impaired/
  - Rivenburgh, K. (2019). *The PDF Accessibility Guide: How to Make Your Portable Documents Accessible* [Website]. Medium. Retrieved 15 April 2020 from https://medium.com/@krisrivenburgh/the-pdf-accessibility-guide-how-to-make-your-portable-documents-accessible-6e77a21a098f
- **How to write alt-text and image descriptions:**
  - Veroniiiica. (2018). How to write alt-text and image descriptions for the visually impaired [Website]. Perkins: School for the Blind. Retrieved 15 April 2020 from https://www.perkinselearning.org/technology/blog/how-write-alt-text-and-image-descriptions-visually-impaired
  - University of Leicester. (n.d). Writing effective ALT text [Website]. University of Leicester. Retrieved 15 April 2020 from https://www2.le.ac.uk/webcentre/plone/build/basics/add-images/alt-text

Planning for dissemination

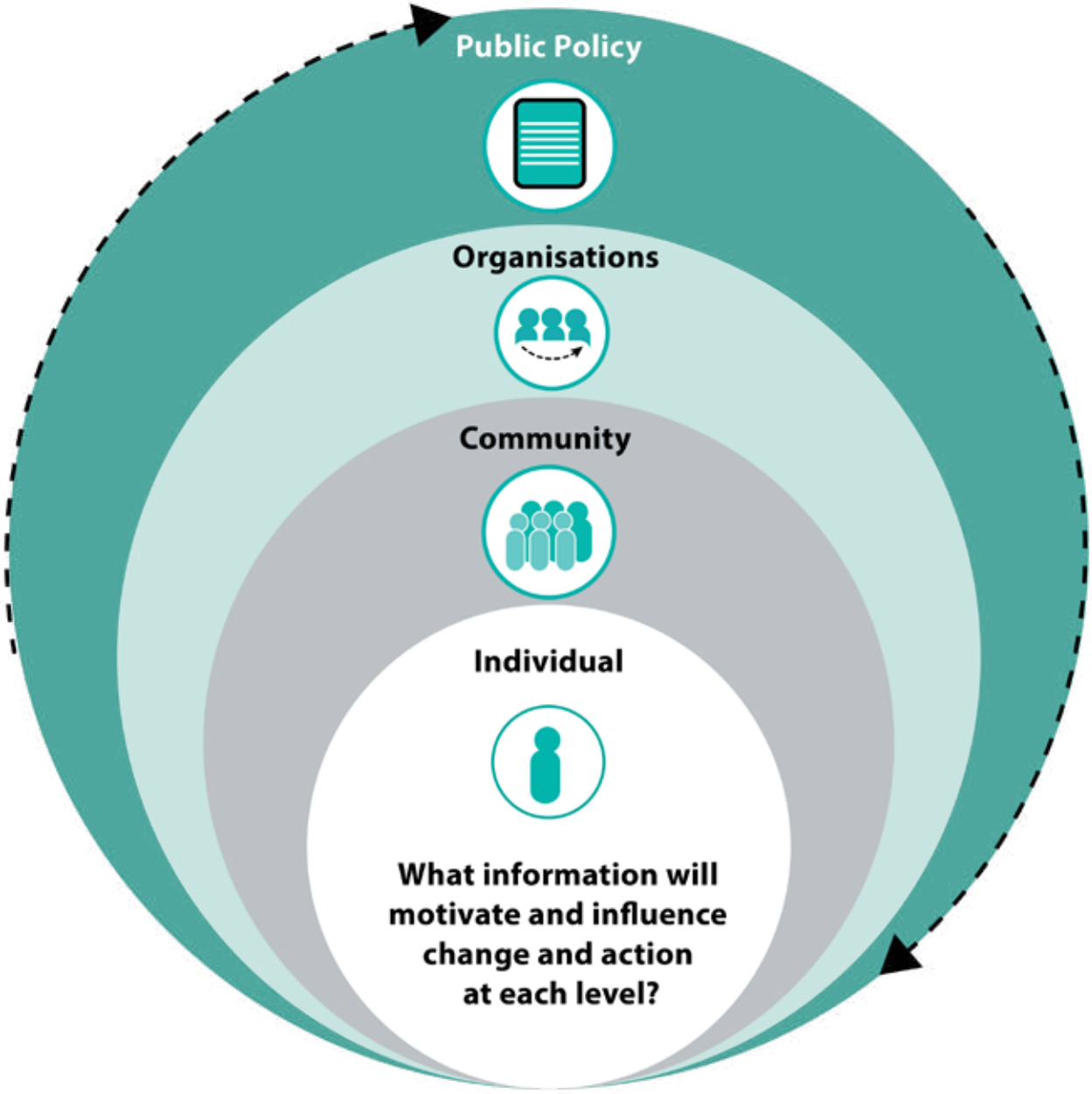
It is recommended that researchers 'plan for impact' by developing a research communication and engagement plan during the research design process. This plan should target and/or involve those stakeholders who are in the best position to make positive changes to practice. The plan should outline the most effective strategies for reaching those stakeholders with the research findings.

Fit-for-purpose research products and communication strategies are more likely to influence the right stakeholders at the right time to create lasting change (RDI Network, 2017a). See **Figure 15**.

Additionally, stakeholders and individuals who have participated in the research should have access to the research findings in ways that are accessible and meaningful for them. Keep in mind that the communication and engagement plan should be revisited often as the research progresses and results emerge.

Consider how co-researchers with disabilities and participants are able to access and share the research. People with disabilities (including DPOs) who are involved in the research design and implementation can contribute to the planning by identifying organisations and individuals within their networks who may be interested in the results and findings. This may mean support is required for stakeholders to translate the research findings and/or recommendations into policy and programming outcomes, as well as for them to be empowered to take action.

Figure 15: Consider the different mediums required by different stakeholders to influence decision-making



Key Resources and Further Reading:

- CBM. *Disability Inclusive Development Toolkit* [PDF]. Retrieved 8 April 2020, from https://www.cbm.org/fileadmin/user_upload/Publications/CBM-DID-TOOLKIT-accessible.pdf
- CHANGE. (n.d.). *How To Make Information Accessible: A guide to producing easy read documents* [PDF]. Retrieved 8 April 2020, from https://www.changepeople.org/getmedia/923a6399-c13f-418c-bb29-051413f7e3a3/How-to-make-info-accessible-guide-2016-Final
- DID4All. (2017). *Australian Government Department of Foreign Affairs and Trade (DFAT) Disability Inclusive Development Helpdesk Response: Accessibility Guideline*. See: www.DID4All.com.au for secure access to document for DFAT staff.
- RDI Network (2020). *Enhancing Research Impact in International Development: A Practical Guide for Practitioners and Researchers*. Authored by: Georgeou, N., & Hawksley, C. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2020/02/ERIID_V8_DIGITAL.pdf

Entry Points: Practice Across the Research Cycle

Entry Point 1: Embedding inclusive practices within the research cycle and process, breaks down entrenched inequalities and empowers local communities. This ensures that all research routinely involves the experience of marginalised and vulnerable people as co-researchers and participants, so that development outcomes are effective and relevant to **all** members of the community.

Entry Point 2: The research cycle can be categorised into four phases; planning, design, implementation, and dissemination. Each phase involves several considerations to organise and consider for disability-inclusive development. Ensure that sufficient time, resources and budget are dedicated to each phase.

Entry Point 3: The **planning phase** involves identifying and developing key partnerships with people with disabilities and their representative organisation, understanding the cultural context and environment for people with disabilities, and involving people with disabilities as advisors, co-researchers and as participants. This may mean including capacity-building activities as part of the research process to ensure that the research design and data collection is collaborative, and not extractive in nature.

Entry Point 4: There is a difference to approaching research with a disability-inclusive lens and providing reasonable accommodation to people with disabilities to allow their participation. Disability-inclusive research seeks to identify the barriers to participation and designs a process that addresses these barriers. On the other hand, reasonable accommodations are changes to an existing barrier on request. This can look like printing all materials in large print with visual cues for all persons use ***or*** adapting one piece of material in large print with visual cues because a person with a disability asked to be included.

Entry Point 5: Reasonable accommodation is a **legal requirement** in many countries. A request for reasonable accommodation must be addressed as soon as possible, if not immediately. Reasonable accommodation includes the provision of an interpreter for a deaf person, a report printed in Braille or large-sized print, and/or ensuring that a meeting location is accessible for a person using a wheelchair or has limited mobility.

Entry Point 6: The **design** and **implementation** phases seek to include and encourage people with disabilities to participate as co-researchers and research participants. This ensures that the research questions, methodology, and data collection methods are appropriate and sensitive to people with disabilities. This is particularly pressing because they make up a large minority in the community and utilise the same services and amenities as people without disabilities. Research projects that include people with disabilities do not need to have a specific focus on disability to be inclusive.

Entry Point 7: Identifying people with disabilities and categorising their functional impairments (disaggregation of data) to investigate trends, gaps and experiences requires appropriate data collection methods. The **Washington Group on Disability Statistics** have developed robust tools to support such measurements with sensitivity and relevance.

Entry Point 8: The **implementation phase** seeks to empower people with disabilities to participate in the research process as participant recruiters, data collectors, and data analysts. This may require adapting collection methods and/or capacity-building activities to ensure that all partners in the research team are able to participate and contribute equally.

Entry Point 9: The **dissemination phase** ensures that people with disabilities are acknowledged as contributors to research, informed of the research findings, and have access to research findings in appropriate formats for their own lobbying and advocacy activities. This may include disseminating research in unconventional methods such as infographics, animations, toolkits, exhibitions and/or performances.

Entry Point 10: The process of disability-inclusive research is ensures that people with disabilities are both agents and beneficiaries of development. To include people with disabilities takes planning and thoughtful consideration of the systemic barriers in our society. Embedding an inclusive approach ensures that all lived experiences and ways of knowing are valued and understood.

Conclusions

Disability-inclusive research is a vital component of disability-inclusive development. The knowledge and understanding of the lived experiences of people with disabilities is essential across the development programming cycle, regardless of whether or not a project has a focus on disability. Achieving this within research requires development researchers to resource people with disabilities and effectively partner with their representative organisations.

This *Research for All* guidance aims to support development researchers to ensure people with disabilities have the same opportunity as people without disabilities to contribute to, and benefit from, development research and evaluation. Ultimately, this is to ensure that people with disabilities have the same access and chances to frame the research and development agenda.

This guidance also makes clear the ethical considerations inherent to all research through the lens of disability-inclusion, to ensure our work and its contributions safeguard the rights of people with disabilities, as well as guarantees the respect of people with disabilities. Safeguarding the rights of people with disabilities involves embedding disability-inclusive processes and outcomes into development to continually address the structural and power differentials at the heart of social inequalities.

Further Resources and Reading

General principles for inclusive research

Guidance and recommendations for engaging in ethical disability health research in cross-cultural settings that intersects with and upholds the CRPD.

- Durham, J., Brolan, C., & Mukandi, B. (2014). The Convention on the Rights of Persons With Disabilities: A Foundation for Ethical Disability and Health Research in Developing Countries. *American Journal Of Public Health*, *104*(11), 2037-2043. https://doi.org/10.2105/ajph.2014.302006

Guidance, practical tools, and templates for meaningful engagement with stakeholders, as well as enhancing research impact throughout the research cycle.

- RDI Network (2020). *Enhancing Research Impact in International Development: A Practical Guide for Practitioners and Researchers*. Authored by: Nichole Georgeou and Charles Hawksley. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2020/02/ERIID_V8_DIGITAL.pdf

Ethical research and evaluation in development

This DFAT-funded website contains resources, toolkits, reports and guidance on a variety of disability-inclusive development work, including but not limited to accessible infrastructure and communications, data collection, education, governance, health and ageing, livelihoods, WASH and women with disabilities. See the 'Resources' tab for more.

- *DID4All: Disability-inclusive development resource* [Website]. CBM-Nossal Institute Partnership for Disability Inclusive Development. https://www.did4all.com.au/

This webpage contains documents that outline steps in research approval for Asia (Cambodia, Indonesia, Laos, Nepal, Philippines, Sri Lanka, Timor-Leste and Vietnam) and the Pacific (Cook Islands, Fiji, Kiribati, Marshall Islands, PNG, Samoa, Solomon Islands, Tonga and Vanuatu).

- RDI Network. (2017b). *Conducting Research in the Region: Ethics Approval Processes*. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/resources/conducting-research-in-the-region/

This guide outlines processes involved in formal publication of research and evaluation. It describes information relating to access to Human Research Ethics Committees, assessment of risk and the ethics requirements of a range of Australian publications in the international development sector.

- RDI Network. (2018). *Ethics Requirements for Research Publication: A guide for Australian researchers, NGOs, and Independent Practitioners* [PDF]. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2017/08/Ethics-Requirements-for-Research-Publication-FINAL.pdf

This guideline contains concise advice for those who fund and conduct research with people with intellectual disabilities in cross-cultural contexts. Helpful advice is provided for research design, research conduct and informed consent.

- Dalton, A., & McVilly, K. (2004). Ethics Guidelines for International, Multicenter Research Involving People with Intellectual Disabilities 1, 2, 3, 4. *Journal Of Policy And Practice In Intellectual Disabilities*, *1*(2), 57-70. https://doi.org/10.1111/j.1741-1130.2004.04010.x

Partnerships and collaborations

This guideline describes different types of partnerships, the importance of effective partnerships, and processes for building meaningful partnerships and collaborations in international development research and evaluation.

- RDI Network. (2017c). *How to Partner for Development Research: Effective approaches to collaboration and partnerships in international development research and evaluation* [PDF]. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2017/01/How-to-Partner-for-Development-Research_fv_Web.pdf

This document offers a starting point for identifying potential in-country research partners in Cambodia, Indonesia, Laos, Myanmar, Nepal, Timor-Leste. Information current as of 2017.

- RDI Network. (2017d). *Research Institutions and Organisations: Asia* [PDF]. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2017/08/Research-Institutions_Asia_Final.pdf

This document offers a starting point for identifying potential in-country research partners in fifteen countries within the Pacific. Information current as of 2017

- RDI Network. (2017e). *Research Institutions and Organisations: Pacific* [PDF]. RDI Network. Retrieved 8 April 2020, from https://rdinetwork.org.au/wp-content/uploads/2017/08/Research-Institutions_Pacific_Final.pdf

Data collection and analysis

This practice note presents an overview of disability inclusive development practice and the need for data to support this; some key issues and principles to consider when collecting disability inclusive data, and methods and tools than can be used to gather data with both adults and children with disabilities.

- Plan International Australia, & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development. (2015). *Practice note: Collecting and using data on disability to inform inclusive development* [PDF]. Retrieved 8 April 2020, from https://www.cbmuk.org.uk/wp-content/uploads/2016/05/plan-cbm-nossal_disability-data-collection-practice-note_july2015_1607.pdf

This guidance provides an overview of the characteristics of quantitative research and basic research designs for quantitative studies. References within the guidance point to more detailed statistical procedures for quantitative analysis.

- University of Southern California. *Research Guides: Organizing Your Social Sciences Research Paper: Quantitative Methods*. University of Southern California Libraries. Retrieved 8 April 2020, from http://libguides.usc.edu/writingguide/quantitative

This guidance outlines what thematic qualitative analysis is, the phases of conducting this type of analysis, and teaching strategies for conducting training in thematic analysis and qualitative methods.

- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning, *26*(2), 120-123. Retrieved 8 April 2020, from https://uwe-repository.worktribe.com/output/937596

Other:

This paper discusses the realities of implementing the CRPD in Solomon Islands, arguing that that post-colonial institutional structures, power relations and globalised political economy of Solomon Islands are major impediments to implementation of the CRPD. Although specific to Solomon Islands, issues highlighted may be useful for cross-cultural considerations.

- Gartrell, A., Jennaway, M., Manderson, L., & Godden, N. (2016). Making the Invisible Visible: Disability Inclusive Development in Solomon Islands. *The Journal Of Development Studies*, *52*(10), 1389-1400. https://doi.org/10.1080/00220388.2015.1121238

This paper draws on the authors' experiences as a team of university based and community-based researchers, and reflections of inclusive research in practice in an Australian university, drawing on a framework of reflexive solidarity. Implications for universities and research institutes are discussed.

- Vaughan, C., Khaw, S., Katsikis, G., Wheeler, J., Ozge, J., Kasidis, V., & Moosad, L. (2019). 'It is like being put through a blender': inclusive research in practice in an Australian university. *Disability & Society*, *34*(7-8), 1224-1240. https://doi.org/10.1080/09687599.2019.1603103

This guidance document provides DPOs participating in research practical information, tools and reasonable expectations for the research cycle. This guidance supports DPOs on making decisions, identifying suitable partnerships, and obtaining useful results for advocacy.

- Leonard Cheshire Disability and Inclusive Development Centre. *Research Toolkit for Disabled People's Organisations: How to undertake and use applied research* [PDF]. University College London. Retrieved 8 April 2020, from http://globaldisability.org/wp-content/uploads/2016/02/Research-Toolkit-for-Disabled-Peoples-Organisations-Leonard-Cheshire-Disability-Published-Version-1.pdf

This community toolkit provides the tools for practitioners, researchers and communities for challenging discrimination against women with disabilities.

- Heng, C., Tep, D., Tith, H., Ton, D., Vallins, N., Walji, F., & Astbury, J. (2013). *Challenging Discrimination Against Women with Disabilities: A Community Toolkit* [PDF]. Banteay Srei, CDPO, CBM Australia, IWDA and Monash University. Retrieved 8 April 2020, from https://iwda.org.au/assets/files/Triple-Jeopardy-Community-Toolkit.pdf

Appendices

PLANNING PHASE

Developing partnerships

☐ Is there a relationship with the local research organisation and/or DPO?

☐ Is there an understanding of the capacities and strengths of the DPOs.

☐ Stakeholder analysis? ☐ Policy analysis? ☐ Program & service mapping?

☐ Do you have a partnership agreement?

☐ Have you explored other possible local partnerships?

Ensuring relevent and useful research

☐ Do you understand the local context in which the research is situated?

☐ Have you analysed any secondary research?

☐ Is there a relationship between disability and the area of research?

☐ Are there factors that (dis)encourage the inclusion of disabled people?

☐ How do various stakeholders see disability inclusion?

☐ How does this influence policy and programming?

Planning for inclusion

☐ Have you identified **all potential barriers** throughout the research process?

Have you secured an adequate budget for:

☐ reasonable accommodations? ☐ paying and resourcing partnerships?

☐ hiring people with disabilities? ☐ team training for disability-inclusion?

Planning for reasonable accommodation

☐ Is the meeting room wheelchair accessible?

☐ Can a local sign interpreter be booked?

☐ Is information available in an accessible format (ie. Braille or large print)?

Refusing to provide reasonable accommodation when requested constitutes as discrimination on the basis of disability

Approaches for capacity-building in disability-inclusive research

☐ Have you identified existing skills and gaps in knowledge in the team?

☐ Disability-inclusive training ☐ Skills training ☐ Participatory sessions

☐ Are there processes for the team to reflect on inclusivity?

☐ How will the feedback be heard and/or changes made when necessary?

☐ Have capacity-building activities been considered in the budget?

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DESIGN PHASE

☐ Is the type of research design being considered disability-inclusive?

Have you considered:

☐ Co-production? ☐ Participatory action research approach?

☐ Strengths-based approach? ☐ Do-no-harm approach?

☐ Have you consciously identified barriers to include people with disabilities?

☐ Have you identified locally developed solutions to incorporate into the methodology and the budget?

☐ Is the methodological approach accessible and suitable to people with disabilities? What tools is the team using to do that?

☐ Are you planning to disaggregate by disability?

☐ What type of sampling have you considered for your research?

IMPLEMENTATION PHASE

☐ How will people with disabilities and their representative organisations engage meaningfully in the research?

☐ How will data collection methods be fully accessible to people with disabilities?

☐ Is there equal compensation for researchers with disabilities?

☐ Will you deliver all aspects of the research process in an accessible manner?

☐ Have the team adapted the data collection methods?

☐ Have you considered accessible locations and communication methods?

☐ Have people with disabilities been included as data collectors and researchers?

☐ Do people with disabilities feel comfortable and welcomed to participate?

☐ Has a risk assessment been made to ensure the safety (emotional and physical) of participants with disabilities? How will that risk be assessed?

DISSEMINATION PHASE

☐ How will research findings be available to partner organisations, local communities and the wider research community?

☐ Are images of disabled people positively depicted and part of the community?

☐ How will people with disabilities actively participate in the dissemination?

☐ Has budget been allocated for the dissemination in accessible formats?

☐ Are people with disabilities and DPOs included, acknowledged and credited?

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Appendix 2: Factsheet B from the W-DARE guidelines outlines inclusive principles and strategies to promote inclusion of people with disabilities in research
Download from https://wdare.wordpress.com/

INCLUSION PRINCIPLES	ACTIONS
RESEARCH AIMS AND OBJECTIVES	
Research must provide tangible benefits to people with disabilities, and work toward greater inclusion of people with disabilities in the community.	• Research aims to improve outcomes for people with disabilities and their communities. • Ensure that DPOs and representative organisations can use research findings to help achieve their own aims and objectives.
PROGRAM DESIGN	
People with disabilities should be involved in identifying the research problem and methods for conducting the research.	• Consult with, and listen to, people with disabilities about their ideas for research: including strengths to draw on and barriers to be addressed to promote their participation in how the research is conducted.
OWNERSHIP	
People with disabilities and DPOs have a degree of ownership over research design, implementation and evaluation, and dissemination and use of research findings.	• Involve people with disabilities in all levels of decision-making from the outset. • Ensure research decision-making processes are open and transparent.
PARTICIPATION	
Ensure that people with disabilities are included as active participants throughout the research as decision-makers, advisors, researchers, trainers etc.	• Establish and formalize partnerships with DPOs and representative organisations from the outset. • Allow people with disabilities to negotiate their own participation in research, including remuneration, scope of involvement and capacity development needs. • Involve DPOs or representative organisations in all decision-making regarding the involvement of people with disabilities in research. • Establish ongoing practices that support inclusive research such as capacity building, clear expectations and responsibilities, policies and procedures.
ETHICS	
Researchers must apply processes of ethics approval that ensure that people with disabilities are included in research as active and willing participants. This includes harm minimisation, ownership and informed consent.	• Seek ethical approval to conduct research (if applicable). • Conduct disability inclusive research ethics training with all team members. • Conduct a risk assessment to ascertain risks and their probability, and whether the risks outweigh benefits to participants. • Develop and adapt informed consent processes (Plain Language Statements and informed consent forms) to ensure people with different impairments can provide informed and free consent.

Factsheet reproduced from ***Promoting disability inclusion in sexual and reproductive health research and programming: Experiences from W-DARE***, pp 41-42. Download from https://wdare.wordpress.com/

DISABILITY AWARENESS	
Researchers and other stakeholders are aware of disability and its implications, and of the importance of including people with disabilities in research. **Research is conducted in a culture of inclusion.**	• Provide disability inclusion training to all involved in research which is facilitated in collaboration with people with disabilities and their representative organisations. • Maximise opportunities for people with disabilities to be 'visible' in the community when involved in research (e.g. data collection, consultations, presentations etc.).
STRENGTHS BASED APPROACH	
Utilise a 'strengths based approach' that recognises the contribution that people with disabilities can make to research, and builds on their existing strengths.	• Identify and highlight the strengths of people with disabilities and DPOs involved in the research and provide opportunities for them to contribute and build on these strengths.
COMPREHENSIVE ACCESSIBILITY	
Barriers to participation in research for people with disabilities are addressed. **Information about the research process, research tools, and research reports are provided in formats that are accessible.** **Recognise the diversity within the disability community and the impact of age, gender, socio-economic status, education, geographic location and impairment type on the opportunities of a person with a disability to participate in research.**	• Tailor recruitment methods to most effectively reach different groups of people with disabilities. • Provide appropriate remuneration for participation (salary for participant-researchers, cover travel expenses and payment time for participants). • Conduct a disability needs assessment and plan for inclusion when applying for funding and designing program budgets and work plans. • Adapt existing participatory research approaches and methods to ensure they are accessible for people with disabilities. • Refer to "Fact Sheet D. Strategies for addressing barriers to participation experienced by people with different types of impairments".
DISSEMINATION OF RESEARCH FINDINGS	
People with disabilities have opportunity to contribute to the development and drafting of research outputs, and are involved in their dissemination. **Voices of people with disabilities are visible in research findings.**	• Involve DPOs in the development of a dissemination plan for sharing research outputs. • Store research findings and outputs in a shared and accessible space, such as a dropbox folder • Involve people with disabilities in the interpretation and analysis of research findings (to facilitate accurate representation of participant voice. • Ensure opportunities for co-production and delivery of publication, presentations and written reports etc. • Acknowledge people with disabilities and their contribution to the research in all research outputs.

Appendix 3: Checklist for participant information form and participant consent form

- ☐ The short, plain-language title of the project.

- ☐ A brief, plain-language statement of the project aims and potential benefits.
  The statement should acknowledge if the project is being conducted to meet the requirement of a qualification, e.g. a university degree. Also, any sponsorship of the project by government or non-government organisations should be acknowledged.

- ☐ The names and contact details of those responsible for the project, including those with overall administrative responsibility and those with local responsibility.

- ☐ The name(s) and contact details of the authority(ies) who has/have approved the project.

- ☐ A description of what the participants are expected to do, where they should be expected to participate and over what period of time.
  This description should include acknowledgment of any audio or video recording that could be involved in either research activities or date collection.

- ☐ A clear statement of any potential risks or discomfort for participants or those with whom they live, work or socialise. Information about how any adverse events will be addressed.

- ☐ A clear statement of any potential benefits to participants and any possible limitations to these benefits (e.g. for the duration of the project).
  Including any compensation for their participation or costs they might incur as a consequence of their involvement in the research.

- ☐ Details of how data is to be collected, stored and later destroyed or preserved. Details of how the privacy and confidentiality/anonymity of participants are to be maintained.
  Also any limitations on the maintenance of confidentiality and/or circumstances where information might need to be disclosed to a third party (e.g. reporting any disclosure of abuse).

- ☐ Details of how the findings are to be disseminated, including how the confidentiality of individual participants is to be maintained.

- ☐ A statement of how participants will be advised and/or can find out about the findings other than through the peer-reviewed literature. Information about whether and how individuals can gain access to data to assist with their usual support or treatment.

- ☐ A statement that the person has been given a signed copy of the Participant Consent Form.

- ☐ A statement guaranteeing the participants' right to withdraw at any time, without having to give a reason or in any way having an adverse consequence for them personally (e.g. the cancellation or alteration of any support service and/or treatment they would ordinarily receive).

- ☐ Contact details of an independent authority to whom participants can direct any inquiries or concerns that they may have about their involvement in the project. *The independent authority should be readily accessible at a local level. However, contact details for the principal ethics committee should also be included.*

- ☐ A signed statement (by the person or legal guardian) that the participant has read, or had read to them, the Participant Information Sheet (which they can keep for their own records), that they understand what participation in the project involves and that they agree to participate on the understanding that they can withdraw their consent at any time without prejudice to their usual services and/or treatment.

- ☐ The Participant Consent Form should also provide for the consent of a 'Legal Guardian' or 'Person Responsible', where the person is unable to provide informed consent independently.

    - ☐ For example, in the case of a person whose disabilities limit their decision-making capacity, or a minor (**Note:** the age of consent varies between jurisdictions and across cultures).

    - ☐ The reason why someone other than the participant is signing the form should be documented (e.g. the person did not understand the consent process or was not deemed legally competent). In such circumstances, the relationship between the participant and the person providing the consent should be detailed.

    - ☐ There should be a clear statement that the person providing the consent on behalf of the participant does so without any inducement or likelihood of personal gain as a consequence of providing consent.

    - ☐ There should be a clear statement that even though someone else signed the Participant Consent Form, if the participant does not provide assent to proceed (i.e., they protest or choose not to comply with the procedure), their participation will cease immediately.

- ☐ Pages on any Participant Information Sheet or Participation Consent Form should be clearly numbered in the format 'Page 1 of 2', and so forth.

Reproduced from Dalton, A. J., & McVilly, K. R. (2004). Ethics guidelines for international, multicenter research involving people with intellectual disabilities 1, 2, 3, 4. *Journal of Policy and Practice in Intellectual Disabilities*, *1*(2), 57-70.

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Appendix 4: Tips on communicating with people who have a variety of impairments

General tips for communication and engagement

- Talk directly to people with disabilities, rather than to people who might be assisting them (e.g. interpreters, family members, personal assistants).
- Ask people with disabilities how they prefer to communicate, where they prefer to meet, where they prefer to sit in meetings, etc.
- Do not single out people with disabilities within a group, or unnecessarily refer to or ask about their disability.
- Be aware that many people with disabilities may feel reluctant to speak out in group situations, or be unused to having their opinions asked. Find ways to promote their participation.
- Be aware that communicating and participating in activities can be tiring for many people with disabilities, and ensure plenty of breaks.
- When communicating with a whole community or a group of people with different types of impairments, use more than one type of communication – for example, material in both written and oral forms.
- If working with Disabled People's Organisations, seek out disability-specific DPOs. Some groups, for example people with psychosocial impairments, deaf and hard of hearing people, and people with intellectual impairments, may be excluded from mainstream DPOs.

Tips to include people with vision impairments

- Ask how people prefer to access written material (e.g. Braille, large print or electronic format) and provide materials in this format as much as possible.
- Read out loud descriptions of written material or pictures that are used in any meeting or event.
- In a group meeting or event, introduce all the people present. Have speakers identify themselves every time they speak.
- Try to make sure only one person speaks at a time in meetings.
- Tell a person with vision impairment if you are leaving the conversation or room.
- Offer assistance with mobility, but do not assume it is required or try to lead someone without asking.
- If a person with vision impairment would like you to guide them, have them take your arm and walk half a step ahead of them, and tell them about steps or obstacles. Further guidance on this can be found at https://www.visionaustralia.org/information/family-friends-carers/guiding.

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Tips to include deaf people and people who are hard of hearing

- Note correct terminology: as per the World Federation of the Deaf designation, the correct way to refer to people with hearing loss is 'deaf or hard of hearing', rather than other terms such as 'hearing impaired'. People who refer to themselves as deaf or Deaf (capitalised) typically are members of the Deaf community and use sign language to communicate, often as a first language. Hard of hearing people may have acquired hearing loss later in life, and may not identify as members of the Deaf community.
- Ask a person what type of communication is best for them – e.g. sign language, lip reading, with assistance from a family member.
- If a person uses sign language it is important to ensure they can access a sign language interpreter. Address the Deaf person directly rather than their interpreter.
- When there are no sign language interpreters, close family members might be able to interpret for the person, with consent from the deaf person. Working with individuals, families, and DPOs representing Deaf people to determine how best to ensure potential participants understand what the research involves, if and how they would like to participate, and how best to ensure a balance between privacy and the right to participate.
- If a person can lip-read: look directly at them, make sure they can see your lips and speak clearly, but do not exaggerate or speak more slowly than normal.
- Use multiple different types of communication: pictures, writing, demonstrations, etc.
- Make sure only one person speaks at a time in meetings and encourage people to raise their hands before speaking so the person can follow the conversation (particularly if they are lip reading).
- Ask people where they would like to sit so they can follow the conversation better.

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Tips to include people with intellectual disabilities

- Use clear language, simple words and avoid long sentences.
- Use pictures and photos instead of lots of words.
- Do not speak to adults or teenagers/youths like they are children.
- Repeat information and demonstrations to help understanding.
- Use hands-on (practical) activities and give examples.
- Give people lots of time to understand and think about what is being said.
- Remove other distractions in a room to help people focus.
- Seek specific guidance on ensuring informed consent for people with intellectual impairments (see Appendix 5 of this guide).

Tips to include people with psychosocial impairments

- Some people may require more notice of events/activities in order to prepare themselves, and they may benefit from reminders of upcoming events.
- Be accepting of different ways of communicating and participating, and make reasonable adaptations when needed. For example, you may need to give extra time for people to respond to questions, or you may need to provide information in smaller pieces so it is more easily understood.
- Keep discussions calm, and do not make people feel as though you want to end a conversation or leave them out of interactions.
- Some people might feel uncomfortable being in a very big group, so make arrangements for a smaller group meeting if necessary.
- If a person seems like they are not interested, give them encouragement to participate.
- Treat the person with respect at all times and ask their opinion in discussions.
- Be flexible and give opportunities for people to make a choice about how they want to participate in a meeting – some people might feel worried in situations where they do not have any control.
- If it is a new activity for a person, check with them if they prefer to have a support person attend with them.
- Be accepting of behaviours that are different to what you are used to - it is important to lead by example and not allow bullying or teasing.
- Ensure that there are frequent rest breaks throughout activities as people may get tired or lose concentration more quickly.
- Some people may feel restless and need to walk around to feel calm - you can help by leaving the meeting door open and allowing people to come and go when needed.

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- If a person appears distressed, ensure you assist them in the same way you would people without disabilities (e.g. listening to their concerns or asking if they are ok if they look worried, asking if there is someone you can link them to for help, etc).
- Seek specific guidance on ensuring informed consent for people with psychosocial disability.
- Tips to include people with physical impairments.
- Do not touch or move someone's mobility aids or wheelchairs without their permission.
- Try to sit or stand so that you are talking at eye level (rather than looking down at someone e.g. a wheelchair user).
- Ensure that venues for events and activities are accessible, including toilets.
- Leave sufficient space between tables, in aisles, etc. for wheelchair users and others who use mobility devices to comfortably move around.
- If someone's impairment affects their speech, give them sufficient time to communicate. Listen respectfully and do not guess or try to speak for them, or cut them off. If you do not understand, ask the person to repeat themselves or clarify with them whether you have understood their message correctly.
- If a person is supported by a caregiver or assistant, address the person directly.

Appendix 5: Example for providing information (Plain Language Statement) in accessible formats

UNIVERSITY of the NORTH PACIFIC
Centre for Research

(insert address)

(insert ethics ID)

 **Easy to read**	This information has been written for you
	You may need help to read this information You may need help to understand what this information means to you
	You can ask a support person to read this information with you
	Maxine Divine is doing the research Maxine is a researcher from the University of the North Pacific
TITLE	The research project is called: "Perceptions of school to life after school transition support for young people with disabilities"
	You can help: • Maxine understand how the service helped you move into your life after school • Maxine identify how to improve the service to help when young people with disabilities are moving into life after school.
?	You can choose: • to be involved in the research **OR** • not to be involved in the research

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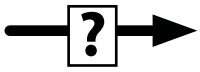
What happens if you are involved in the research?

You can choose a time and place like home or somewhere else you feel comfortable to meet Maxine for the interview.

The interview goes for about 60 minutes



Maxine will ask you questions about your experience of the Services supports during your transition from school to life after school

You can have a support person with you

If you agree, Maxine will audio record your answers and write notes while talking with you.

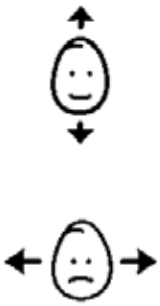
You can stop the interview at any time

You can stop being part of the research at any time

What happens to my information?

Maxine will keep your information safe

- Locked in a filing cabinet
- Locked in a computer file



Maxine must have your permission before you can be involved in the research.

If you want to be involved in the research you must fill in the form called 'Consent Form'

If you DO NOT want to be in the research, you can say no now.

If you need more information:

Contact Maxine.

Email: (insert email)

Call or text: (insert contact number)

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UNIVERSITY of the NORTH PACIFIC
Centre for Research

(insert address)

(insert ethics ID)

PARTICIPANT CONSENT FORM

I, ...**[PRINT NAME]**, give consent to my participation in the research project.

TITLE: Perceptions of School to after school life transitions for young people with disabilities

INSTRUCTIONS: Present the participant with the following statements and ask them to decide whether each one is **true or false**. Circle their responses.

If the participant answers incorrectly, discuss the correct response, referring back to the Information Statement. When the participant seems to understand their mistake, ask the same question again.

1. Participating in this research project involves meeting and talking with Maxine Divine, a researcher from the University of the North Pacific.

True or False

2. The researcher will meet with you one time. **True or False**

3. The researcher will ask you questions about your transition from school to post school and how the Service may have helped you. **True or False**

4. You have to participate in the research project. **True or False**

5. The researcher can share personal information about you with others.

True or False

6. You can withdraw from the study at any time. **True or False**

7. I am giving my consent to:

i) Audio-taping **True or False**

ii) Receiving Feedback **True or False**

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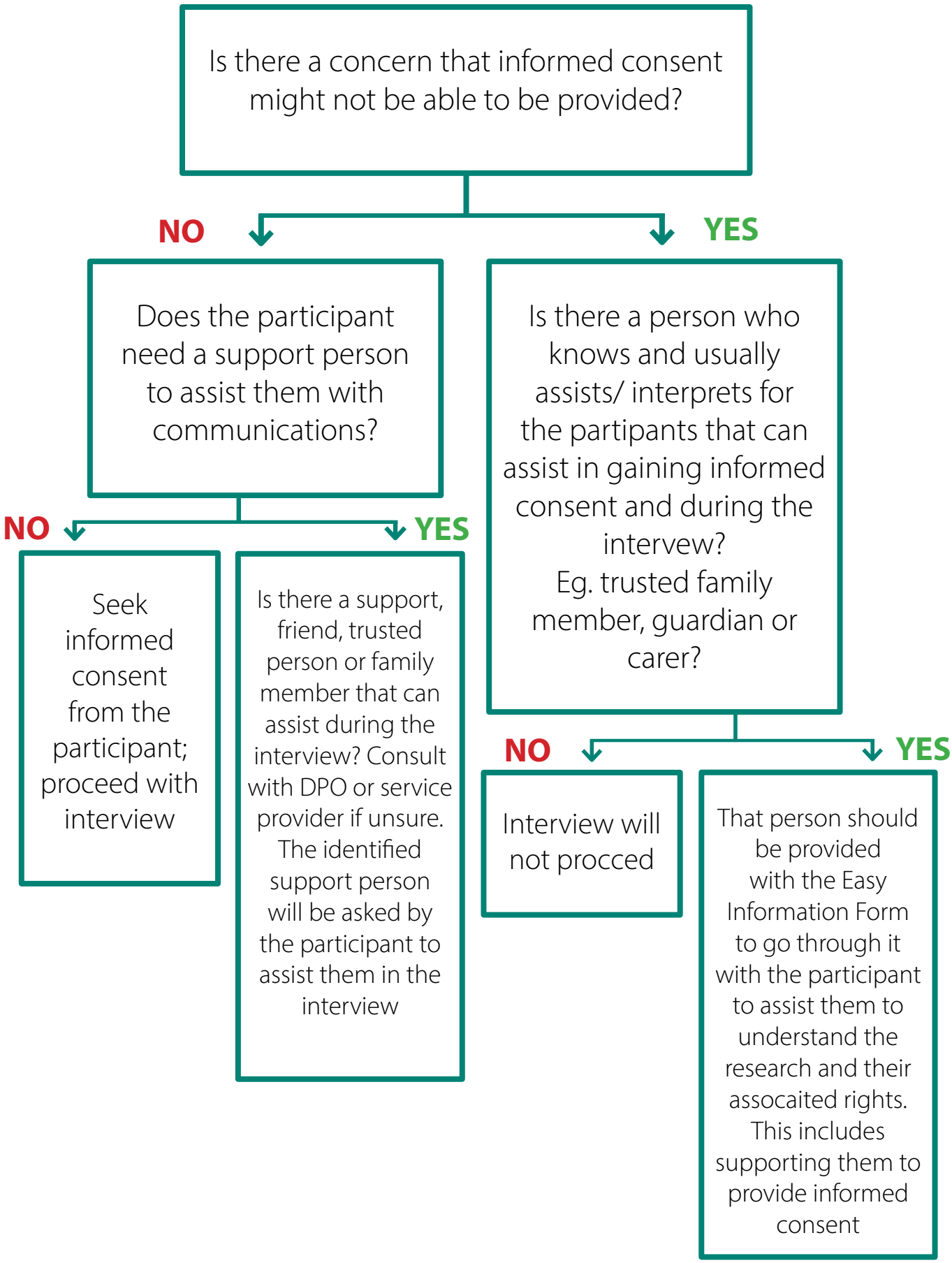
Appendix 7: Decision tree for determining the process for informed consent



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Six tips for planning and running inclusive meetings and events

Ensuring meetings and events are inclusive – not just of people with disabilities, but of a diverse range of people – benefits all attendees and ensures everyone can participate. This document offers six tips to guide organisations in making community level events and meetings inclusive. These provide a starting-point: given that local contexts and individual needs will vary widely, it is best to ask people with disabilities what supports they require to fully participate.

1. Identify and specifically invite people with disabilities:

- ✓ Ask a local Disabled People's Organisation[1] (DPO) or self help group for advice on how to get the message out to people with disabilities in the community and invite them to participate.
- ✓ Ensure that all invitations and material used to advertise events show that people with disabilities, the elderly etc are welcome and that the event is accessible.
- ✓ Use a variety of methods to advertise the event: for instance, radio as well as newspaper; or contacting the women's group as well as the village head.

2. Find out whether particular assistance or support is required to enable attendance and active participation in your meeting/event:

- ✓ Ensure written and verbal invitations ask questions such as the following:
  Do you require any additional support to enable you to participate (like sign language interpreters or accessible transport)? If yes, please let the organisers know so that we can best meet your needs.
- ✓ Ensure that it is clear who participants should contact.

3. Ensure promotional and meeting material is accessible:

- ✓ Ask how people prefer to access written material (e.g. Braille, large print or electronic format) and provide materials in this format wherever possible.
- ✓ Try and present information in both visual and audio formats. For example if you are showing a picture or a chart, also explain what is in the chart, Likewise, if you are talking, make notes of the key points or show picture/charts.
- ✓ Use signs in large print and clear font to guide people to the venue.

[1] Disabled People's Organisations (DPOs) are organisations made up of persons with disabilities and which exist to represent the interests of their members.

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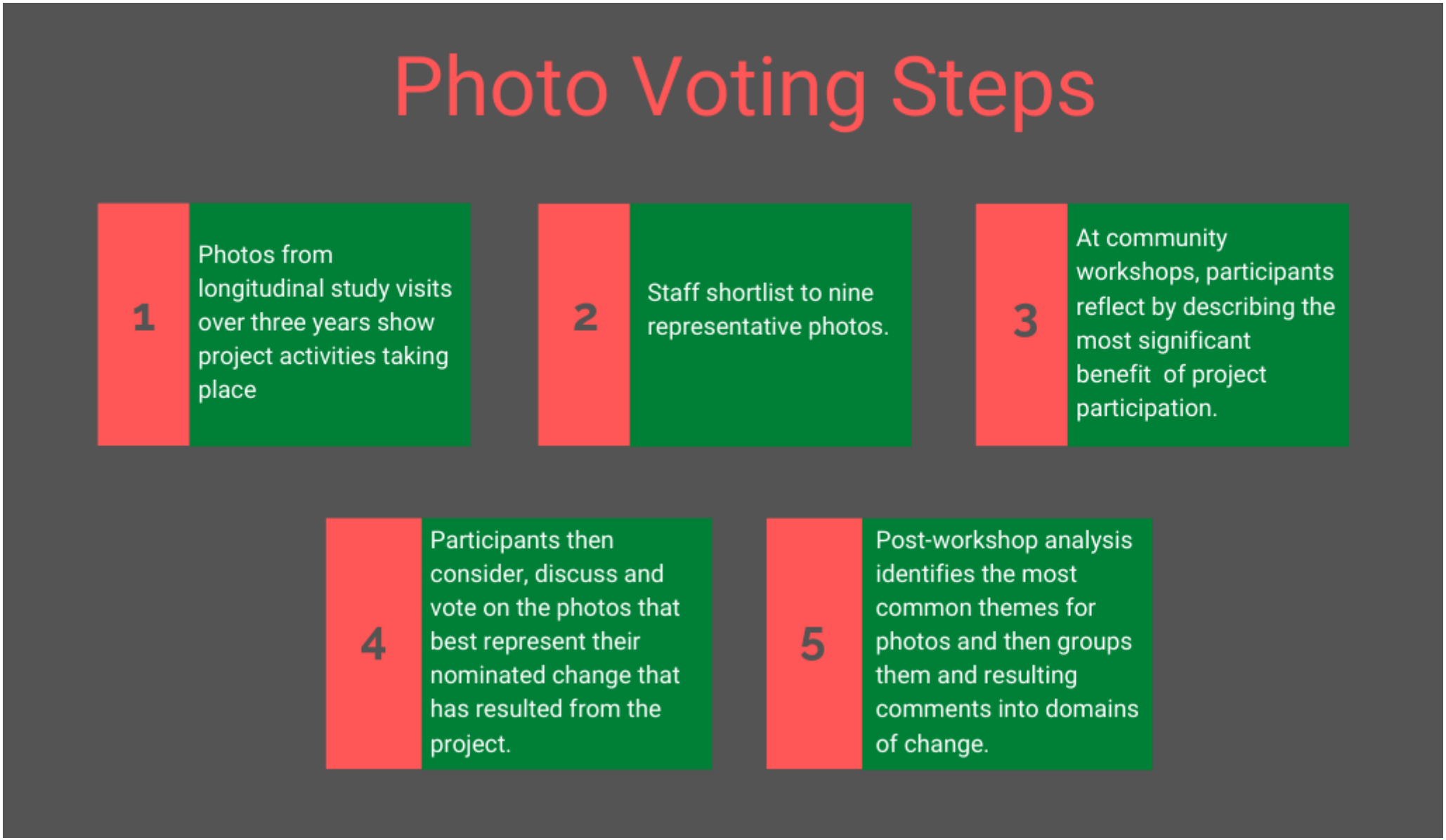
Appendix 9: 5 Steps to Photo Voting (PV) - reproduced with permission from Conor Ashleigh / World Vision Australia © 2020



Step 1:
Photos of longitudinal study visits over three years show project activities taking place.

This is a photo of SALP staff practicing taking photos as part of the SALP storytelling training provided by the consultant.

Step 2:
SALP staff shortlists the photos to nine representative photos.

Step 3:
At community workshops, participants reflect by describing the most significant benefit of project participation.

This is done by sharing physical prints of the photos.

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Step 4:
Participants then consider, discuss and vote on the photos that best represent thier nominated change that has resulted from the project.

Voting takes place individually and anonymously.

Step 5:
Post-workshop analysis identifies the most common themes for photos. Photos are then thematically grouped, resulting in tangible and visible stories of change.

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Appendix 10: CBM-Nossal Plan practice note: Collecting and using information about disability throughout the project cycle. (Table 2). Reproduced from *Practice Note: Collecting and using data on disability to inform inclusive development* (2016), pp 16-17. Download from https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf

Table 2: Collecting and using information about disability throughout the project cycle

Project cycle stage	WHY collect information about disability?	WHAT do we want to know?	WHERE can we find this information?	HOW to collect it?	WHO should be participating?
Situation analysis and project design	• To better understand the local situation/context • To target programming where it will be most effective	• Who are the people with disabilities in our target communities? • What are their opinions, experiences and situations, and how do these differ among men, women, boys and girls? • What are the local understandings and attitudes about disability? • What disability organisations exist? • What barriers prevent people with disabilities from accessing programs/services and participating fully in their communities?	• Data on the prevalence, types and causes of disability • Qualitative information on people with disabilities' own experiences • Mapping of DPOs, services, laws, programs, etc • Evidence and analysis of attitudinal, physical, communication and institutional barriers to inclusion	• Participatory Learning and Action (PLA) tools • Focus group discussions (FGDs) • Household/baseline surveys • Key informant interviews • Existing data/info: public data, local DPO/community-based rehabilitation/service provider records	*At all stages of the project, engage with:* • Women, men, girls and boys with disabilities, including people with a variety of impairments (physical, vision, hearing, intellectual and psychosocial impairments) • Carers and household members of people with disabilities • Local or national DPOs or other groups of people with disabilities • Disability service providers or other disability-focused organisations • Other community members, local leaders, government duty bearers, civil society organisations, NGO staff
Planning, targeting and start-up	• To ensure the most marginalised communities/individuals are targeted and included • To plan for access and inclusion (including active decision making) within the project design and budget	• Who are the women, men, girls and boys with disabilities in our target communities? • What are the barriers to participation of people with disabilities in our project? • What are the enablers for people with disabilities to use their strengths and capacities to participate/contribute? • What strategies or adaptations are needed to ensure universal access? • Who needs to be explicitly involved in the project to ensure inclusion?	• Identification of people and households affected by disability • Views and opinions of people with disabilities about barriers and enablers • Assessment of barriers to participating in project activities • Analysis of key stakeholders • Identification and costing of required accessibility actions	• Existing data sources • PLA tools • FGDs • Baseline surveys (with questions to enable disaggregation) • Outreach/door to door visits • Key informant interviews • Screening participants • Accessibility/inclusion audit	
Implementation – monitoring, reflection and improvement	• To monitor who is participating/ benefiting and who is not – and why • To make adaptations and improvements to project activities to make them inclusive	• Who is participating and who is not? • Is participation of people with disabilities genuine and meaningful (not tokenistic)? • What enabling factors or barriers affect inclusion of people with disabilities? • How are the project outcomes working for people with disabilities? • What are the different experiences of women, men, girls and boys with disabilities? • What changes are needed to strengthen inclusion?	• Monitoring data on participation, access and outcomes for people with disabilities • Views and opinions of participating people with disabilities • Information from key stakeholders/ partners • Analysis and reflection on barriers/ challenges and enabling factors (in the project and external)	• Participants' stories and views • Staff/stakeholder/beneficiary feedback • Disaggregated monitoring data • Qualitative monitoring • Disability-specific indicators/ markers • Reflection processes	
End of program – evaluation, reflection and learning	• To evaluate what changes have taken place • To capture learning about inclusive practice	• What changes have taken place in terms of rights and inclusion of people with disabilities? • To what extent were people with disabilities included in the project? • What factors enabled or hindered inclusion? • What are the opinions, voices and views of women, men, girls and boys with disabilities about the project?	• Evidence of changes related to disability inclusion among rights holders, duty bearers, civil society and project staff • Views, opinions and experiences of people with disabilities • Analysis of project learnings related to inclusive practice	• Reflection processes • Endline surveys (with questions to enable disaggregation) • Key informant interviews • Disability-sensitive evaluation questions • Disability-specific indicators/ markers • Participants' stories and views	

Note: This table reflects some of the key elements to consider at each stage of the project cycle. In reality, however, collecting data and strengthening disability inclusion is not a step-by-step, linear process. Tackling disability exclusion will involve testing, learning and adapting strategies to address the complexity of each local or national context and respond to opportunities which may arise throughout the project cycle.

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Appendix 11: Washington Group Short Set of Questions (WG Short Set)

The Washington Group (WG) Short Set is a set of questions designed to identify (in a census or survey format) people with a disability.

The WG Short Set was **not designed** to be used in isolation. Rather, they should be used in conjunction with other measurement tools. For more information, please see http://www.washingtongroup-disability.com/

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

3. Do you have difficulty walking or climbing steps?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

4. Do you have difficulty remembering or concentrating?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

a. No - no difficulty **b.** Yes – some difficulty **c.** Yes – a lot of difficulty
d. Cannot do at all

Appendix 12: CBM-Nossal Plan Practice Note: Overview of methods and tools for collecting data to support disability inclusion (Table 3).

Table 3: Overview of methods and tools for collecting data to support disability inclusion

isaggregating ata by sability	A process of breaking down data into subgroups and comparing data from each of these subgroups (e.g. men, women, boys and girls with and without disabilities) to learn about their different situations and experiences across a range of indicators or domains.	• Can highlight issues that might otherwise remain invisible in general community level data, particularly for marginalised community members • Enables comparison and analysis of diverse experiences • Can point to issues for further investigation using other methods	• First requires identifying people with disabilities (see below) • Can be seen as a reporting or compliance issue • Needs follow-up data analysis focused on learning about and responding to the diversity of situations and experiences of different groups	Applies to all data collection processes, particularly those with large numbers of participants such as surveys or project monitoring tools. Should be complemented with more in-depth methods to hear various perspectives and learn about why different groups have different experiences.
sing measures ‘functioning’	Various sets of questions that ask people about basic activities or major body functions, such as whether they have difficulty walking, seeing or communicating. These provide an approximate way to identify most people who might have a disability. (Examples: Washington Group Short Set and Extended Set of Questions on Functioning)	• Provides a more sensitive and accurate way to collect data on disability prevalence than directly asking if someone has a disability • Avoids using language such as ‘disability’ or ‘handicap’ or other words which might be seen as stigmatising • Can be undertaken by staff or community members with a small amount of training	• Provides only an indication of disability, not a diagnosis • On its own, does not provide information about the barriers a person faces in their community • Requires training of data collectors and care to avoid focusing on a person’s limitations (particularly where staff are more familiar with medical approaches to disability)	To identify people who might have a disability in order to: • Disaggregate survey or other data; • Follow up to learn more about their situation and priorities; • IInclude people with disabilities in development projects or activitiesEstimate disability prevalence within a community; and/or • Refer people to specialist services.
ool: ashington roup (WG) hort Set of uestions	A set of 6 questions for identifying the most common types of functional difficulties and thereby providing an approximation of disability prevalence. It is the most widely used measure of functioning and is recommended by the UN for use in population-based surveys.	As above, plus: • Has already been tested and translated into many languages • Provides a standardised and internationally comparable method for estimating disability • Shorter and simpler to use than other measures of functioning	As above, plus: • Only identifies the most common types of functional difficulties (e.g. might miss mental health issues) • Has not been validated for use with children aged under 5; mainly designed for use with adults • Should be used exactly as developed to maintain validity	Can be incorporated into surveys, questionnaires, project registration sheets, monitoring tools, etc. to allow for disaggregating data or promoting individuals’ participation in a project. Particularly relevant where there is a rationale for collecting population and project data using internationally standardised measures.
lentifying ildhood sability	Sets of questions to be used with parents/carers to identify childhood disability are still under development (as of 2015) by the Washington Group and UNICEF.	As for measures of functioning, plus: • Provides a standardised way of estimating disability at different stages of childhood development	As for measures of functioning, plus: • Parents/carers might not recognise or want to disclose disability • Should be complemented with child-friendly/participatory methods	Particularly relevant for projects targeting vulnerable children, and/ or which have a focus on learning and research on prevalence and experiences of childhood disability.
nowballing’ nd informal echniques	A process of locating people with disabilities by talking to key informants (e.g. health workers, village leaders or volunteers) and having them refer project staff on to other people with disabilities they are aware of through various networks.	• Puts value on (and benefits from) local knowledge, participation and informal networks • Can locate people who might be hidden/missed by formal surveys • Can be easily used at any stage of a project	• Does not use a standard definition of disability • Care should be taken to avoid labelling people as ‘disabled’ or causing stigma or shame	Particularly useful for projects where people with disabilities are a target group and where generating standardised data is not a priority. Can also be used as part of project efforts to strengthen local networks and relationships.

Reproduced from *Practice Note: Collecting and using data on disability to inform inclusive development* (2016), pp 30-31. Download from https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf

Methods for identifying people with disabilities	**Using existing data**	Involves using secondary local data from various sources, e.g. health provider or school records, census/ survey results, NGO reports/records, and the records of Disabled People's Organisations (DPOs) or community-based rehabilitation (CBR) networks	• Takes advantage of existing local data and knowledge on disability • Avoids duplicating surveys or other data collection activities • Can quickly and cheaply help provide an indicative snapshot of a local disability context	• May be incomplete, under-reported or partial (e.g. measuring only one type of disability or only adults) • Care should be taken to consider the data collection methods and understandings of disability underpinning each data source	Can provide a starting point for project design and planning – e.g. by identifying target locations and stakeholders – but will typically need to be complemented by more in-depth and localised data collection.
	Household and individual surveys	Adding WG questions (or other measures of disability) to questionnaires enables surveys to: identify people who might have a disability; estimate disability prevalence; and disaggregate data across all survey questions. Specific questions on equity and inclusion should also be included.	• Provides a broad picture of disability and inclusion across various aspects of community life • Including questions on functioning (e.g. WG questions) enables identification of differences in experiences and outcomes between people with disabilities and other groups	• Can be time consuming for data collectors and survey respondents • Resource constraints may limit surveys to the household level and overlook intra-household inequities • Needs complementary data collection to better understand individuals' perspectives and experiences	Questions to disaggregate data should be included in all surveys. At the planning stage, a baseline survey can inform situation analysis and identify barriers to inclusion which projects will need to address. End-of-project surveys can compare outcomes among different groups within a community.
	Tool: Rapid Assessment of Disability (RAD)	A survey toolkit with questionnaires and guidelines designed to collect a baseline on disability and inform inclusive programming. It includes questions to identify individuals with disability and assess demographics, wellbeing and access/participation.	As above, plus: • Provides a way of understanding and measuring how disability impacts upon wellbeing and access to services and rights • Identifies a wider set of functional limitations than the WG Short Set	As above, plus: • Requires translation of the survey and training of data collectors	Can be used as a stand-alone disability-focused survey, or adapted into a comprehensive project baseline/ endline by adding individual RAD components to other surveys or customising the RAD questionnaires.
	Key informant interviews and focus group discussions	Interviews and discussion groups are important sources of data and should include people with disabilities, their carers and household members, DPO members, and disability NGO or service-provider staff.	• Can provide detailed qualitative information about the situations, experiences and views of people with and without disabilities, including the local context and understandings of disability	• Men, women, boys and girls with disabilities may feel uncomfortable participating in mixed groups • Processes/methods may need be adapted to ensure all people can access them and participate	At all stages of a project. Can help provide a snapshot of the disability context and the views of people with disabilities at planning stage, and help planners select appropriate further data collection approaches.
	Participatory Learning and Action (PLA) approaches	A range of participatory methods and tools which can enable people to share knowledge and experiences, analyse local conditions, identify appropriate responses and reflect on projects in their community.	• Empowers participants and values local knowledge/experience • Uses accessible or easily adaptable techniques • Allows for diverse perspectives • Can raise awareness of disability and challenge attitudes/beliefs	• Does not use standardised approaches to disability • Care should be taken to avoid stigmatising people with disabilities or emphasising separateness • Some people might not feel comfortable in group activities	At all stages of a project, but especially at planning/start-up to inform localised, context-specific responses. Particularly relevant to projects focused on promoting social inclusion and working with marginalised community members.
	Tool: Accessibility audits	A participatory process whereby people with disabilities attend a particular location or facility and assess any barriers or enablers to its accessibility.	• Empowers participants as data collectors and analysts • Can raise awareness among planners and decision-makers	• Might only reflect the perspectives of a limited number of participants • Might only identify physical barriers • Should be supplemented with specific design/building standards	Can be applied to facilities and venues being used, built or upgraded by a project, as well as to broader barriers to participation in a community or project.

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