USAID OKARD

Social and Behavior Change Communication
Strategy and Action Plan

REACHING FOR A BETTER LIFE

USAID Okard (ໂອກາດ) supports Disability Inclusive Development In Lao PDR

Acknowledgement

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Acronyms

AP	Assistive Products
ARMI	Association for Rural Mobilization and Improvement
CBID	Community-Based Inclusive Development
CCEH	Center of Communication and Education Health
DID	Disability Inclusive Development
DMAS	Disability Mainstreaming Advisory Services
DSC	Disability Service Center
FGD	Focus Group Discussion
GoL	Government of the Lao People's Democratic Republic
HoH	Hands of Hope
HI	Humanity & Inclusion
INGO	International Non-Governmental Organizations
KAP	Knowledge, attitudes and practices
MoH	Ministry of Health
MoLSW	Ministry of Labour and Social Welfare
NCD	Non-communicable diseases
NCDE	National Committee for Disabled People and the Elderly
NRP	Naturalized Role Play
OPD	Organization of Persons with Disabilities
OT	Occupational Therapy
P&O	Prosthetist and Orthotists

QLA   Quality of Life Association

SALT   Speech and Language Therapy

SBCC   Social and Behavior Change Communication

TVET   Technical and Vocational Education and Training

UNCRPD   United Nations Convention on the Rights of Persons with Disabilities

USAID   United States Agency for International Development

WCPT   World Confederation for Physical Therapy

WEI   World Education, Inc.

WHO   World Health Organization

Foreword

The United States Agency for International Development (USAID) Okard project supports Disability Inclusive Development (DID) in Lao PDR. World Education, Inc. implements USAID Okard in partnership with the National Committee for Disabled People and the Elderly (NCDE), the Ministry of Labour and Social Welfare, the Ministry of Health, Humanity & Inclusion (HI), and civil society organizations.

USAID Okard contributes to addressing multiple factors that, all together, enhance and empower persons with disabilities to effectively participate in family and social life, education, employment, and recreational activities on an equal basis with others. Even if health, rehabilitation, and social service systems are improved to better meet the needs of persons with disabilities, many barriers still need to be identified and acknowledged, and tangible actions need to be taken to achieve full and effective participation. Therefore, USAID Okard employs Social and Behavior Change Communication (SBCC) as a cross-cutting approach to DID.

The way we talk about or to a person with disabilities, the way we look or do not look at a person with disabilities, are probably the most sensitive barriers to participation perceived and experienced by persons with disabilities and their family. Attitudinal barriers are behaviors, perceptions, and assumptions that discriminate against persons with disabilities. These barriers often emerge from a lack of understanding, which can lead people to ignore, to judge, or to have misconceptions about a person with a disability.

The SBCC Strategy and Action Plan titled "Reaching for a Better Life" developed by USAID Okard, is based on evidence from the literature review and compiles and analyzes several testimonies shared by a diverse representation of the Lao society. "Reaching for a Better Life" aims to help stakeholders understand and celebrate *'human diversity'* through the lens of different levels of functioning, access to services, empathy, dignity, equity, and non-discrimination.

The review of findings from broad consultations, Group Discussions and role play exploring dilemmas, and issues around health, caregiving, employment, and community engagement has allowed the identification of several recommendations that, if implemented by stakeholders, will create effective changes to our understanding and perceptions of the lives of persons with disabilities, ultimately enhancing the inclusion of persons with disabilities in society.

My wish for those reading "Reaching for a Better Life" is twofold.

First, to share the assumption that if we acknowledge and admit that our own attitudes toward persons with disabilities might sometimes hurt, disempower, or even humiliate people, this is the first step in initiating an individual, social, and behavior change.

Second, to support and encourage all of us to contribute to reaching a better life for persons with disabilities and their families by considering the strategic recommendations and implementing these proposed actions in our personal and professional lives.

Last but not least, I would like to share my deepest respect and appreciation to all persons with disabilities and their families who shared their stories and experiences, as they are the key to ensuring we all understand how to better celebrate human diversity.

Kind regards,

Bernard Franck
Chief of Party - USAID Okard, World Education, Inc.

INTRODUCTION

I. Introduction

Culture exerts a profound influence on the way in which people think and what they think. An individual's beliefs produce their worldview. The beliefs, ideas, and values of individuals and society contribute to the behaviors and actions within homes and the wider community. Beliefs and attitudes about disability are individually experienced but often socially constructed. Persons with disabilities are significantly affected by the way disability is understood, explained within society, and how people behave.[1] In Lao PDR, there are multiple, deeply rooted factors that influence and lead people to think and act differently towards persons with disabilities.

To address these barriers, USAID Okard aims to catalyze change by exploring what communities know, how they think, believe, and decide to act and behave towards persons with disabilities and their families. The Social and Behavior Change Communication (SBCC) Strategy and Action Plan is an active, intentional, and an ongoing engagement with the concepts of disability and human diversity that aims to promote the full participation of persons with disabilities within their communities.

This SBCC Strategy and Action Plan, titled "Reaching for a Better Life" has been developed to guide and support the USAID Okard Activity to influence and change people's attitude, perception and behavior towards disability by beginning to explore and understand each other, moving beyond simple tolerance to celebrating human diversity, encouraging changes in behavior that ultimately supports the inclusion of all people in a community.

The process to design the SBCC Strategy and Action Plan followed multiple steps, and from November 2019 to February 2020, included a situation analysis, stakeholder consultation, community consultation, strategy design, intervention design workshops, strategy roll-out, SBCC trainings for sub-recipients and the beginning of SBCC interventions implementation. Moving forward, SBCC interventions will continue with monitoring, reflection and analysis to determine the outcomes of interventions, which will eventually lead to an evaluation of the SBCC Strategy and Action Plan towards the end of the USAID Okard Activity.

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[1] Culture and Belief Systems (Chapter 4), Nothing About Us Without Us: Disability Oppression and Empowerment, James I. Charlton (2000)

Social and Behavior Change Communication (SBCC) Strategy and Action Plan Timeline

November 2019
Situation Analysis:
A literature review of existing formative assessment and data to gather key relevant facts to inform strategy design.

January 2020
All Stakeholders Consultation:
Situation analysis finalized and presented the concept and essence of SBCC to all USAID Okard stakeholder

January 2020
Community Consultation:
A supplementary data gathering workshop to fill information and knowledge gaps as well as to validate insights and inferences of findings from station analysis.

January-February 2020
Strategy Draft:
Draft strategy including finding, rationale, objectives and audiences were developed with inputs from all stakeholders and representatives from community from the two consultations.

November 2020-Present
SBCC Intervention Implementation:
Ongoing SBCC intervention implemented by sub-recipients. SBCC coordinator will follow up, monitor and evaluate (M&E) quarterly . The USAID Okard sub-recipients share and reflect their lesson learned with one another to improve the quality of their interventions and increase community dialogues on disability inclusion.

June-July 2020
Strategy Roll out and SBCC Basic Training:
Updated SBCC Strategy and Action Plan rolled out to USAID Okard sub-recipients along with SBCC basic training to create a solid foundation of SBCC principles, tools, skills and knowledge among all sub-recipients and facilitators who will be involved in implementing the SBCC strategy. This was conducted in Vientiane, Savannakhet and Xieng khouang

February 2020
Intervention Design Workshop:
SBCC findings, audiences, objectives, audiences and strategic approaches were presented to all sub-recipients. Each sub-recipients developed a full plan potential SBCC interventions to address the key findings and achieve the goals and objectives effectively.

This SBCC Strategy and Action Plan consists of nine sections:

Section 1: Introduction provides an overview of what the Strategy and Action Plan is, its purpose within the USAID Okard Activity and briefly describes each section of the SBCC Strategy and Action Plan.

Section 2: Background introduces information about the context of disability in Lao PDR, including the prevalence of disability, the causes of disabilities, and the Government of Lao People's Democratic Republic (GoL) efforts to strengthen systems and service provisions to meet the needs and support requirements of persons with disabilities. This section also introduces the goal of USAID Okard Activity and how it aligns with government strategies to improve and sustain the independent living and functional ability of persons with disabilities and presents the key processes of data collection and analysis utilized to develop the SBCC Strategy and Action Plan.

Section 3: Research Findings and Recommendations presents the data collected and analyzed and transforms this into primary findings and recommendations revealing the key issues connected to stigma, discrimination and social exclusion of persons with disabilities. Each finding has a recommendation on how to address issues through tangible actions on disability inclusion.

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Section 4: Rationale for the Strategy Design connects the SBCC recommendations with seven strategic implications as the foundational knowledge used to develop the SBCC strategic goals, objectives, approaches, audience, messaging framework and interventions.

Section 5: Strategy Goals and Objectives shares the two SBCC goals and six objectives that will address the SBCC recommendations.

Section 6: Strategic Approaches explores the five key approaches to drive action and behavior change in communities to create inclusive environments. This includes how to improve the quality of inquiry about disability and rehabilitation, interactive communication methods based on dialogue rather than dissemination, magnifying impact through synergies across media and processes, and how to use role models for successful change.

Section 7: Audience and Messaging Framework presents the different primary, secondary and tertiary audiences targeted in the SBCC Strategy and Action Plan, and the two key message sets related to disability inclusion for all audiences, and specific messages on health and rehabilitation for healthcare providers.

Section 8: Interventions presents the SBCC interventions each USAID Okard sub-recipient will implement including a detailed description of the specific methods. and how these interventions will contribute to the achievement of specific SBCC goals and objectives to address changes in knowledge, attitudes and behavior.

Section 9: Monitoring Plan for the SBCC Strategy and Action Plan provides information on indicators, methods and data sources in order to measure changes and determine the impact of SBCC interventions connected to the SBCC goals and objectives.

BACKGROUND

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II. Background

2.1. Disability and health policy in Laos

Lao PDR is a landlocked country in the heart of mainland Southeast Asia, with 18 provinces, including Vientiane Capital, with 148 districts and 8,447 villages.[2] In 2018, the population of Lao PDR was estimated at 7.013 million[3] with 14% over the age of 50 (979,000 people).[4] The country is mountainous, ethnically diverse and predominantly Buddhist (64%).[5] The country reached middle-income status in 2011.[6]

Over one billion people, or about 15% of the world's population, live with some form of disability.[7] Based on these estimates, Lao PDR may have over one million persons with some form of disability. In the Lao PDR, estimates vary on the prevalence of disability. The 2015 Lao PDR census estimated a disability prevalence of 2.8%.[8] Another disability survey in selected areas of Laos in 2016 reported a significantly higher disability prevalence at 10.8%.[9] This variation in the estimates is due to different methods used for measuring disability in the surveys. In the USAID Okard target districts, the Community Based Inclusive Development (CBID) baseline found that 13.3% of people in Kham district and 9.9% in Xayphouthong district were living with a disability.

Specific to Lao PDR is the ongoing risk of injury from unexploded ordnance (UXO) that contaminates fifteen out of eighteen provinces and approximately 25% of villages.[10] During the Vietnam War, an estimated 580,000 bombing missions were carried out over Lao PDR, dropping two million tons of ordnance. This contaminated the country with approximately 80 million items of unexploded ordnance (UXO), including "big bombs," cluster munition and submunition bomblets, grenades, rockets, and other types of ammunition[11]. There also remain an unknown number of landmines across the country. In more recent years, effective mine

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[2] https://laosis.lsb.gov.la/majorIndicators.do?paramGrpId=all

[3] https://laosis.lsb.gov.la/majorIndicators.do?paramGrpId=all#majorIndicatorsConts

[4] https://laosis.lsb.gov.la/tblInfo/TblInfoList.do

[5] WHO Systematic Assessment of Rehabilitation Situation (STARS) (2019), p12

[6] According to the World Bank, middle-income countries (MICs) are defined as economies with a gross national income (GNI) per capita between $1,036 and $12,535., https://www.worldbank.org/en/country/mic

[7] WHO World Report on Disability, 2011

[8] Lao Statistics Bureau, *Results of population and housing census 2015*. 2016, Ministry of Planning and Investment: Vientiane.

[9] Fielding, A., et al., *Improving Access to Social and Economic Services for People with Disability in Lao PDR*. 2017.

[10] Legacies of War http://legaciesofwar.org/about-laos/secret-war-laos/

[11] Community-Based Inclusive Development: Integrating Survivors into a Broader Victim Assistance System," *The Journal of Conventional Weapons Destruction*: Vol. 23 : Iss. 3, Article 10. Available at: https://commons.lib.jmu.edu/cisr-journal/vol23/iss3/10

risk education and the clearance of high-risk areas has caused the number of casualties to drop from 119 in 2010 to 24 in 2019.[12]

Non-communicable diseases (NCDs), particularly cardiovascular disease, cancer, and diabetes are on the rise in Lao PDR that can lead to increases in short- and long-term disability. In 2014, NCDs are estimated to account for 48% of the total deaths in the country.[13] Road traffic crashes are also increasing in Lao PDR. In 2019, there were 6,616 reported road crashes,[14] killing 1,134 (739 male and 395 female) and injuring 10,642 people (5909 male and 4733 female). Of those injured, 1,516 (958 male and 558 female) were left in critical condition. The data show that men are more likely to experience injuries and psychological trauma from UXO and road traffic crashes. As in many countries in the Western Pacific Region, the Lao PDR population is ageing with older people living with increasing levels of chronic disease, frailty and limitations in functioning. In 2010, those over the age of 50 represented 12% of the population; this is expected to increase to 18.9% of the population by 2030. In addition, health conditions including some cases of leprosy remaining in Lao PDR, people living with physical impairments caused by polio, cerebral palsy, club foot and spina bifida, and people living with vision and hearing impairments increases the prevalence of disability.

The GoL has proactively sought to strengthen systems and service provision to meet the needs of persons with disabilities including health and rehabilitation services, mental health and psychosocial support, inclusive education and social protection. Based on the United Nations Convention on the Right of Persons with Disabilities (UNCRPD) and the Decree on Persons with Disabilities 137/GOL, a National Policy, Strategy and Action Plan on Persons with Disabilities (2021-2030) is being coordinated and implemented by the Secretariat of the National Committee for Persons with Disabilities and Elderly (NCDE), Ministry of Labour and Social Welfare (MoLSW). The Policy, Strategy and Action Plan on Persons with Disabilities aims to ensure the participation and inclusion of persons with disabilities. In 2018, Lao PDR passed the Law on Persons with Disabilities which demonstrated the GoL's commitment to supporting and including persons with disabilities.

The Ministry of Health (MoH) has developed and approved the National Rehabilitation Medicine Strategy (2018-2025) in line with the World Health Organization Western Pacific Regional Office (WPRO) Regional Framework on Rehabilitation[15] and WHO's Rehabilitation

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[12] National Regulatory Authority For UXO/Mine Action (UXO-NRA) Sector in Laos Annual Reports

[13] WHO (NCD) Country Profiles 2014: http://www.who.int/nmh/countries/lao_en.pdf

[14] Laos Statistical Information Service, Public works and Transport, accidents, https://laosis.lsb.gov.la/tblInfo/TblInfoList.do;jsessionid=8DDJmkiDtL7HXzHt50Wi0P4M4IRhLFQUAJrMR_hi.laosis-web

[15] WPRO Regional Framework on Rehabilitation (2019) https://iris.wpro.who.int/bitstream/handle/10665.1/14344/9789290618812-eng.pdf

2030 Initiative.[16] This strategy outlines six strategic objectives to scale up rehabilitation medicine.

2.2. Approach and methodology

Social and Behavior Change Communication (SBCC) is an integral, cross-cutting part of the USAID Okard project and is expected to play a catalytic role in increasing knowledge and understanding of disabilities and rehabilitation, helping transform attitudes and practices that lead to social exclusion while improving health-seeking behaviors. The current document addresses the strategic role of SBCC in promoting disability mainstreaming, contributing to changing people's attitudes, perceptions and behaviors towards disability, and encouraging behavior that supports the inclusion of all people with disabilities in the community.

This SBCC Strategy and Action Plan, titled *Reaching for a Better Life*, is driven by quantitative and qualitative evidence and insights gathered from a three-step process as described below.

Step 1: Literature review/desk research: The first step of strategy development was an in-depth literature review to gather key relevant facts to inform strategy design. The main documents reviewed were the (USAID Okard) *Community Based Inclusive Development (CBID) Demonstration Model Assessment – Baseline Survey Report (2020), the USAID Okard Performance Evaluation Baseline (2019), the Disability Monograph of Lao PDR (2018)* using data from *the Population and Housing Census (2015)* and Humanity and Inclusion (HI) *Knowledge, Attitude and Practice* (KAP) *Survey – Linking Disability to Maternal, Newborn and Child Health (2012)*. Also reviewed was information gathered from key informant interviews with persons with disabilities in Xieng Khouang and Savannakhet provinces; and data from Focus Group Discussions (FGDs) on people-centered care and women-centered care that were held in Vientiane (November, 2018) and Kham District, Xieng Khouang Province (December, 2018) to learn from the experiences and perspectives of persons with disabilities on using health and related rehabilitation services.

Step 2: Stakeholder Consultation: In January 2020, the stakeholder consultation workshop was held at the International Cooperation and Training Center (ICTC) in Vientiane with representatives from USAID Okard's sub-recipients and stakeholders including the MoLSW's NCDE, the MOH's Department of Health Care and Rehabilitation (DHR) and the Centre of Medical Rehabilitation (CMR), HI, World Education, Inc. (WEI), the Quality of Life Association (QLA), the Association for Rural Mobilisation and Improvement (ARMI), the Lao Disabled People's Association (LDPA), Disability Mainstreaming Advisory Services (DMAS) Centre, Hands of Hope (HoH) and the Disability Service Center (DSC). Stakeholders provided feedback and insight on the initial literature review research findings.

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[16] WHO Rehabilitation in Health Systems (2017) https://www.who.int/publications/i/item/rehabilitation-in-health-systems

Step 3: Community Consultation: The two-day Community Consultation was a supplementary data gathering workshop to fill information and knowledge gaps as well as to validate insights and inferences. The workshop was attended by diverse participants such as village authorities, teachers, doctors, nurses, caregivers (family members), employers, a monk, a traditional healer, and a pharmacist. Persons with disabilities with a diverse range of health conditions and impairments, including people who were blind, deaf, and those living with limb amputations were also represented each from Vientiane, Xieng Khouang and Savannakhet. The workshop represented a spectrum of age, sex, and ethnicity. Representatives from Central, Provincial and District Governments also participated, including NCDE, MoLSW, DHR, MoH, CMR, the Center of Communication and Education Health (CCEH), Mahosot Hospital, Provincial Labor and Social Welfare Department (PLSW), Provincial Health Department (PHD), Provincial Rehabilitation Center (PRC), District Labor and Social Welfare Office (DLSW), District Health Office (DHO), additional participants from WEI, HI, and representatives from civil society organizations including OPDs; LDPA, QLA, ARMI and the DMAS Center.

The Community Consultation Workshop
in Vientiane on 29-30 January 2020

Photo: Souliya Ounavong / USAID Okard

The consultation was an experiential process that used methods of Naturalized Role Play (NRP)[17] such as simulations and role play enactments in a safe space, with discussions and experience sharing to explore dilemmas and issues around health, caregiving, employment and community engagement among persons with disabilities, their families, and their social networks.

1 Literature review/ desk research

2 Stakeholder Consultation

3 Community Consultation

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[17] Naturalized Role Play (also known as naturalistic role play) is an innovative method developed by Tran as a way to obtaining spontaneous data with the control of social variables. As suggested by the term of 'naturalized', the core basis of NRP embodies the notion of eliciting natural data which closely resemble real life in a controlled setting (Tran, The Naturalized Role-play: An innovative methodology in cross-cultural and interlanguage pragmatics research1,2006).

RESEARCH
FINDINGS AND
RECOMMENDATIONS

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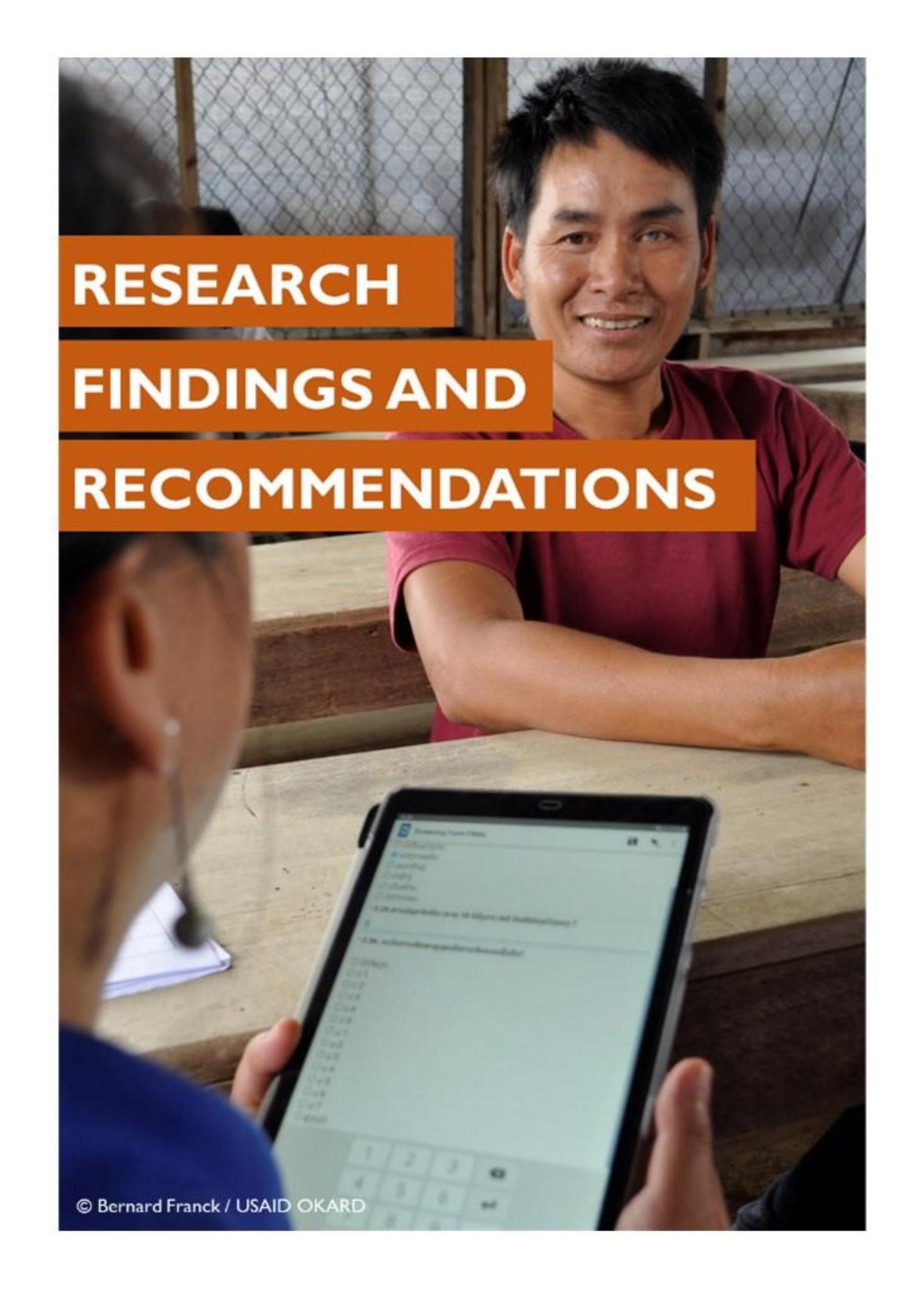
III. Research Findings and Recommendations

Following the three-step data collection process, USAID Okard consolidated reflections and notes into primary findings that inform the development of the SBCC Strategy and Action Plan. The findings summarize the key issues connected to social exclusion of persons with disabilities and provides recommendations to address disability inclusive development within the SBCC strategic plan.

3.1. There is limited knowledge within the community about health conditions that reduce functioning and lead to disability

Disability is viewed in different ways depending on the person's understanding and experiences. People are able to identify and distinguish 'types of difficulties in functioning' but this is limited to visible ones. Knowledge of mental illness and psychosocial disabilities is low among community members with and without disabilities alike.[18]

3.1.1. Family caregivers and parents are unaware of childhood developmental milestones. As a result, parents do not recognize and share concerns, nor seek medical advice in a timely manner when their child experiences delays in developmental milestones. This postpones consultation with medical staff and the detection of difficulties in functioning

Every parent expects the best outcomes when they are having a baby. When a child is born looking healthy, the child is assumed to be fully able, with no difficulties in functioning.

> *"I never thought that my child was autistic. He looks like other children, he is physically strong. But he does not like to communicate with me and does not follow instructions. Our family thought he had not fully grown up yet and was naturally naughty. I was worried so we took him to hospital but they didn't tell us if there was something wrong with him. When he turned five years old, I learned about the Association for Autism in Vientiane and I told my husband to contact them, but my husband still didn't believe that he had a disability because our child looks healthy. So, I contacted the association myself."*
>
> — *Mother of son diagnosed late with autism, Savannakhet.*[19]

It can be difficult for parents to tell when their child has a developmental condition, particularly for children with cerebral palsy, autism and hearing or intellectual impairments that may lead to long term difficulties in functioning. Delayed detection can be due to the family's limited medical knowledge of symptoms, causes and usual developmental milestones. Some families

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[18] CBID Demonstration Model Assessment – Baseline Survey Report (2020) p 72.
[19] Interview of Mother of Son with autism from Association for Autism.

believe that a child who looks healthy and strong, but has difficulties in functioning probably just needs a little more time to develop, and do not usually suspect a health condition.

3.1.2. There has not been a sustained communication campaign either by the Government of Lao PDR or an international agency to create general understanding about health and developmental conditions that could cause difficulties in functioning, or about available medical and rehabilitation options

Lao PDR has had awareness raising and information campaigns that used television advertisements, leaflets, and posters for spreading messages on health promotion and disease prevention, health living and nutrition, road safety and UXO risk education. These campaigns have been carried out by government and non-government actors and have been sustained over a number of years. However, sustained and widespread communication has been limited on health conditions and related difficulties in functioning, and the available medical and rehabilitation options that could optimize functioning and mitigate disabilities.

Many in the community are unaware of health and developmental conditions that lead to difficulties in functioning. As a result, for example, some in the community still believe that disabilities are contagious. Many seek traditional sources for information and help rather than evidence-based medical sources.

One reason for the wide knowledge gap could be that communication campaigns have been few and too short for creating long lasting impact. Another reason could be a mismatch between the media preferred within communities and the media used in the campaigns. For instance, information delivered by word of mouth through a trusted community member might have greater credibility than an elaborate and professionally produced television advertisement.

Recommendation: Curiosity and inquiry about health conditions and related difficulties in functioning, and available medical and rehabilitation treatment, should be encouraged, enhanced, and sustained. Clear and evidence-based information should be provided to persons with disabilities, family caregivers and parents to increase their health literacy.

3.2. Many people understand disability from a historical and traditional perspective from their communities, and encourage the use of traditional practices to address disabilities

Concepts of disability have been changing since the 1970s with ideas and definitions of disability transitioning from individual and medical perspectives to structural and social perspectives in which persons with disabilities are viewed as disabled by society rather than by their bodies. Functioning and disability is a dynamic interaction between difficulties in functioning due to health conditions and contextual factors, both personal and environmental.

Therefore, disability is considered to be complex, dynamic, multi-dimensional and its definition can often be contested by different groups.[20]

While there are many different experiences and understandings of disability, there is an agreed definition in the 2007 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): "persons with disabilities include 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."[21]

In simpler terms, the UNCRPD acknowledges that disability is created and influenced by societal perceptions. A difficulty in functioning due to a health condition becomes a disability when barriers in the environment, including attitudinal, communication, physical, policy, programmatic, and social, restrict and limit the person to participate in society on an equal basis with others. This understanding of disability is most appropriate for a strategy on communication and social and individual behavior change.[22] While the concept and definitions of disability have evolved over time, this understanding and interpretation have not yet been embraced universally across the world in different countries and cultures.

3.2.1. Disability is often misunderstood because it is only seen in medical terms, and as an abnormality that needs to be fixed

When disability is understood solely as a health condition, it ignores or minimizes the barriers that deny a person their right to fully and effectively participate in society on an equal basis with others.

Yet in Lao PDR, disability is primarily recognized within communities only as a visible physical characteristic, as something wrong or missing with the body. Mental illness and psychosocial disabilities are ignored, as are other less visible impairments such as deafness or intellectual impairment. There is little awareness that people's beliefs, attitudes, behaviors, and the environments they live in themselves could be barriers that can lead to disability by preventing effective and equal participation. It is common that communities have not yet been exposed to the interpretation of disability as defined by the UNCRPD.

It is assumed based on the current local understandings of disability there is still a long journey until communities will understand and recognize disability through appreciation, acceptance, and celebration of disability as part of human diversity.

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[20] WHO World Report on Disability (2011)
[21] United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Article 1-Purpose, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html.
[22] United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), p 4.

3.2.2. Traditional and cultural beliefs influence the understanding of disabilities, and propose mystical and spiritual solutions for addressing them

Lao PDR has a rich cultural tradition and spiritual belief system. While Buddhism is the majority religion, animistic beliefs co-exist among all segments of the Lao population. A strong belief in spirits underlies the relationship of Lao people with nature and community. Spirits are often considered the cause of congenital conditions or diseases, and disabilities. Most Lao people believe that spirits co-exist with the living and should be respected and appeased when they become angry or harmful.

Currently, the main traditional and spiritual sources that communities turn to learn about and understand disabilities include:

Shamans: Shamans are generally regarded as having exclusive access to the world of spirits. According to Hmong belief, shamans are chosen by spirits, usually after a serious or long-term illness, typically diagnosed by another shaman and regarded as a spirit-induced confrontation with death. The shaman is contacted so that he may pursue the spirit and bring it back to the body and thus effect a cure. Many Lao homes are protected by spirit houses where people leave daily offerings of food and flowers to keep the spirits happy. Bad spirits and ghosts are also supposed to be able to possess people and bring illness. Spirits are suspected especially when someone becomes unwell without a clear explanation as to why, struggles with unexplained pain, talks to themselves or acts or looks different from others. At such a time, the family of the affected person may seek help from a shaman, who will perform rituals to cast out the bad spirit.

Fortune tellers: A diagnosis (examination to identify the health condition) or prognosis (what will be the likely long-term outcome of the health condition) for a health problem may also be sought from fortune tellers, including astrologers, palmists, dream interpreters, and card readers. The main information people will receive from such fortune tellers relates to luck, sins, karma (the good or bad consequences of actions in this or previous lives), and spirits and ritualistic ways to exorcise the spirits or demons. Both fortune tellers and the rituals they propose can be costly.

Traditional healers (herbalists): Traditional healers are commonly consulted in lieu of a medical doctor especially when a clinic or hospital is far from the person's home or when the illness itself is not considered to be life-threatening. While the MoH is increasingly recognizing the role of traditional healers, it is also clear that these healers are not the complete sources of correct and scientific knowledge about health conditions and related difficulties in functioning that would benefit from medical or rehabilitation treatment to prevent complications or to optimize functioning.

Village authorities, older persons, and neighbors: Community members have high respect for village authorities and older persons, and their recommendations. However, such authority figures, themselves lacking accurate knowledge and understanding of congenital conditions, disease, illness, and disability, may merely repeat information they learned from traditional sources such as shamans and fortune tellers. Neighbors and older persons are influential and often consulted in decision making, but their knowledge too is likely to have come from the same traditional sources mentioned earlier.

3.2.3. People hold fatalistic views of disabilities

Community members often invoke spirits and animistic elements when asked to explain the causes of disabilities. This is often accompanied by a sense of fatalism; a belief or attitude that human beings are powerless to change events, because the disability is viewed as the consequence or even "punishment" for actions in a previous life. Shamans, fortune tellers, or monks and nuns may be consulted for the appropriate ritualistic solutions rather than evidence-based medical treatment or rehabilitation to improve health, prevent complications, and optimize functioning.

According to the CBID baseline findings, there was little evidence at the community-level of an understanding that people with disabilities had any capacity to change their own situations in life. Instead disability was reported in terms of being an inevitability.

> *"We help as much as we can, but it [their fate] is what they [people with disability] are."[23]*

> — *A community member without disability, Savannakhet.*

3.2.4. Some people are reluctant to discuss their traditional beliefs in public

Although many people choose local sources and traditional beliefs for explanations of disability, they are reluctant to identify themselves openly with such beliefs. For example, observations in the all-stakeholder community consultation indicated a strong perception that karma and sins were the cause of disabilities. However, when asked in front of other participants whether they believed disability was caused by karma, only two out of 38 people raised their hands.

Similarly, just a few people spoke up in favor of the finding that "people turn to local sources for understanding disabilities." However, when asked to make their choice anonymously, 19 participants agreed and 19 participants disagreed. By comparing anonymized small-group conversations with plenary discussions of the same topics, it appeared that some people who

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[23] CBID Demonstration Model Assessment – Baseline Survey Report (2020) p. 67

had been open within small groups were hesitant to make the same disclosures in larger groups.

Some participants claimed that most people were educated and did not hold many traditional beliefs about health. Others disagreed, such as one man with visual impairment, who believed that disability must have spiritual or religious roots because it was found even in developed countries with excellent healthcare.

> *"My mother had had good nutrition during her pregnancy and done everything right, and yet I had been born with a disability".[24]*

> — *A man with visual impairment, Vientiane.*

Recommendation: Build capacity of traditional sources such as monks and nuns, shamans, traditional healers, and village authorities to have increased knowledge on health conditions that lead to difficulties in functioning and disability, and available health and rehabilitation services so they can be influenced to recommend medical services alongside traditional practices.

3.3. There is a low general understanding, even among health care providers, of rehabilitation and its positive effects on functioning and prevention of long-term impairment

Historically, rehabilitation in Lao PDR has been provided by prosthetists and orthotists and physiotherapists under the supervision of doctors. Rehabilitation interventions have included the fitting of prosthetic and orthotic devices for people who have lost their limbs in UXO or other types of accidents, and massage, acupuncture, passive mobilization and stretching, and physiotherapy modalities (electrical muscle stimulation, ultrasound, heat, ice) for people that have long-term difficulties in functioning due to injuries or health conditions such as polio, stroke, spinal cord injury, cerebral palsy, or other congenital deformities.

The word rehabilitation itself is unfamiliar to many people, while prosthetics, acupuncture, and massage are more familiar. One quarter of people overall in Kham and Xayphouthong districts reported that they did not know what rehabilitation was. Among persons with disabilities awareness was even lower. Nearly half of persons with disabilities in Xayphouthong District did not know what rehabilitation was.[25]

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[24] Community Consultation Workshop "Reaching for a Better Life" Report, p.20
[25] CBID Demonstration Model Assessment – Baseline Survey Report (2020)

3.3.1. Lack of knowledge about rehabilitation creates a lack of demand and can make rehabilitation services less viable and reduce their quality

People who do not know the benefits of rehabilitation and assistive products (AP) to optimize functioning are less likely to access it. Most people do not seek out rehabilitation on their own without the advice of a doctor first. In addition, a robust, standardized system of referral to rehabilitation centers by doctors does not exist.[26] Thus, when people have difficulties in functioning (even temporary), they may not see any reason to go to a health center when they do not consider themselves "sick." Even among people who do know what rehabilitation is, only 3.3% reported ever needing to access it, meaning demand is still quite low.

This lack of demand for rehabilitation makes it harder for hospitals to justify maintaining rehabilitation staff, much less expanding rehabilitation services or providing them at the district and primary health care (village) levels. For example, one district hospital had only two physiotherapists providing rehabilitation services, since 1990. They discontinued the service in 2008 because it proved cost inefficient to retain therapists to serve only three to five patients per month. Four provinces in Lao PDR are reportedly considering discontinuing physical therapy services because they do not have enough patients.[27]

In some places, health service providers may express negative attitudes and behave negatively that stigmatize and exclude persons with disabilities trying to access health and rehabilitation services. The limited understanding of health conditions that cause difficulties in functioning and lead to disability, combined with negative attitudes and a lack of compassion towards patients causes persons with disabilities and their caregivers to not want to go the rehabilitation center despite needing the service.

3.3.2. Health service providers have limited training on rehabilitation

Only one doctor in Lao PDR is a clinical specialist in rehabilitation medicine, but works in a management role within the MoH rather than providing rehabilitation interventions.[28] There is no rehabilitation medicine specialization in the University of Health Sciences of Lao PDR. Health service providers are generally less informed about rehabilitation and have difficulty explaining it to their clients.[29]

Physical therapists and Prosthetist and Orthotists (P&O) are the main rehabilitation professionals present in the health workforce. Lao training programs exist for these professions, but are not accredited internationally with the World Confederation for Physical Therapy (WCPT) and the International Society of Prosthetics and Orthotics. Neither is there

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[26] WHO Systematic Assessment of Rehabilitation Situation (STARS) (2019), p. 34
[27] WHO Systematic Assessment of Rehabilitation Situation (STARS) (2019), p. 20.
[28] WHO Systematic Assessment of Rehabilitation Situation (STARS) (2019), p 23.
[29] WHO Western Pacific Regional Office Handicap International Lao PDR Program World Education, Capacity Assessment and Development of Plan to Increase Capacity of Laos Rehabilitation Workforce, professor Gwynnyth Llewellyn June 2015.

an established system for continued professional development. Therefore, the knowledge and skills transferred to undergraduates and the clinical practices of PTs and P&Os in the rehabilitation workforce may not reflect up-to-date, evidence-based information and practice. Moreover, Occupational Therapy (OT) and Speech and Language Therapy (SALT) do not yet exist as professions in Laos. Services for mental health and psychological support are also limited with only two psychiatrists and one medical psychologist in Lao PDR.[30]

This limits the opportunity for a multi-disciplinary team to provide rehabilitation interventions to optimize the function of individuals in the different areas of daily living, especially related to self-care, speech, and communication. This is most evident when working with individuals with complex rehabilitation needs such as those living with stroke, spinal cord injury, or cerebral palsy. The scarcity of doctors trained in rehabilitation medicine may result in a low level of referrals for rehabilitation, contributing to the underutilization of rehabilitation.

In general, continued professional development and training opportunities for rehabilitation staff to upgrade skills or qualifications are limited, and are dependent on contract status at MoH (or MoH quota) and seniority of position.[31] When training opportunities are available, lower-level competencies in English language and basic sciences make it challenging for Lao health professionals to meet entry criteria of international education institutions. This also limits the ability to access and use international resources that offer helpful and up-to-date guidelines on rehabilitation interventions for different health conditions. The limited availability of funds further exacerbates all these challenges.

If senior staff do not access the same continued professional development opportunities as junior staff this can lead to disparities in knowledge. This hinders the junior staff applying new knowledge and skills when providing clinical interventions as senior staff are not able to supervise and ensure safe practice. Reluctant to contradict their seniors, junior-level staff may grow frustrated with not being able to use their newer knowledge, and ultimately, if not practiced and applied this knowledge can be lost over time.

Recommendation: Build capacity of health personnel at all levels of the health system to understand the benefit of rehabilitation medicine including assistive products to improve functioning of the population and increase the prescription and referral to rehabilitation services. At the community-level, increase awareness of the population on available rehabilitation services and its benefits.

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[30] CBM (2016). Report from Central East Asia regional Mental health Assessment.
[31] WHO Western Pacific Regional Office Handicap International Lao PDR Program World Education, Capacity Assessment and Development of Plan to Increase Capacity of Laos Rehabilitation Workforce, professor Gwynnyth Llewellyn June 2015. P.22

3.4. Fear and poor understanding of disabilities leads to stigma, teasing, and social exclusion of persons with disabilities

The word stigma refers to the devaluation or negative judgement of a person or a group because of something that makes them different from others. Stigmatization includes two elements: recognizing there is something different about the person (such as a disability) and the negative judgement and devaluating behavior (such as teasing, naming-calling, shaming, excluding from social interactions or denying rights and privileges)[32]. It is worth noting that social stigma comes from the community, but can also come from the person with disabilities towards themselves, known as self-stigma. In self-stigmatization, a person with a disability will see themselves negatively as different and having less worth.

3.4.1. Name-calling is widespread and persons with disabilities are expected to cope with it

In Lao PDR, people often acquire nicknames based on their appearance such as 'Yai' (big) or 'Noy' (small), 'Tui' (fat), or 'Joy' (skinny). For persons with disabilities, this often means being labeled based on the type and appearance of their impairment. For instance, one man living with physical impairment explained:

> *"Sometimes they can make fun of me like calling me 'Mr. Broken Leg,' or 'Mr. Arm Impairment,' what are you doing here?"... But I feel nothing because I know that they are just making fun of me. I don't feel anything, I am an easy person. I make up my mind not to be upset."*
>
> — *FGD, Man living with physical impairment, Xieng Khouang.*[33]

This quote also demonstrates the complicated response to name-calling. The responsibility for coping with the distress caused by name-calling and teasing is placed not on the community, but on the person with disabilities who is expected to not be offended by the teasing at all, or to be mentally "strong" and not get upset. When asked what a young man who is called "Mr. Half-Leg" should do, 20 out of 38 people said he should ignore it when it happens but discuss with the village chief privately. The second most common response (from 16 out of 38 people) was for him to ignore it because it is normal.[34]

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[32] Julio Arboleda-Flórez (Editor), Norman Sartorius (Co-Editor), Understanding the impact of stigma on people with mental illness (2008), p.16

[33] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 79

[34] Community Consultation Workshop "Reaching for a Better Life" Report, p.10

Another woman living with physical impairment reflected that when she was "bullied" and "ridiculed" she could not help but feel upset. "I didn't want to [feel upset], but it just happened."[35]

Roughly 20-25% of persons with disabilities in Kham and Xayphouthong districts noted that "persons with disabilities are subject to unacceptable jokes, comments or humiliation."[36] Most people without disabilities, however, do not see their teasing behavior as mean or stigmatizing.[37] This discrepancy is evident in the data from Kham district, where 33% of persons with disabilities agreed that "people in this village have negative attitudes towards persons with disabilities," while only 18% of persons without disabilities agreed with this statement.

Teasing based on appearance can also be tied to beliefs that disability is a consequence of actions from an earlier life. For example, some people say having a cleft lip at birth could mean that you cursed someone in a past life, or that an arm deformity could mean your mother harmed an animal when she was pregnant with you. One person suggested that one way to stop stigmatizing behavior could be to tell the stigmatizers that in their next life they would look like the person they were teasing.

3.4.2. Persons with disabilities feel that healthcare providers do not treat them with the dignity and respect they deserve

Not only do persons with disabilities experience teasing in their day-to-day interactions within communities, they sometimes also experience disrespect or inappropriate behavior when seeking healthcare. For example, in a focus group of 10 women with disabilities, three reported that health service providers supporting the delivery of their baby had been impolite and disrespectful. One mentioned that the doctor said to her: "Why do you want a child? Do you think you can look after him? You are already a burden to the community."[38]

A man living with visual impairment reported that doctors consistently directed questions to his caregiver (orientation guide) rather than to him directly. Among people who could not access healthcare as much as needed, 5.5% of persons with disabilities said they "did not like attitudes of health staff" and found them to be the most significant barrier to seeking healthcare, while no people without disabilities cited this as a barrier.[39] Negative and discriminatory attitudes within healthcare settings towards persons with disabilities can prevent them from seeking the care that they need and deserve when they are sick.

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[35] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 81
[36] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 77
[37] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 91
[38] FGD People Centered Care, Vientiane 1/11/2018. P 1
[39] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 49

3.4.3. Teasing and stigma is experienced more by younger persons with disabilities compared to older persons, and more by persons with psychosocial impairments compared with persons with other health conditions

While teasing and stigma are widespread towards persons with disabilities, it is more prevalent among younger persons with disabilities compared to older persons with disabilities. Teasing and fear of bullying caused some parents to choose to not let their child with disabilities play in the community or go to school.

Whereas older persons with disabilities that have more respect from the community are less likely to be made fun of, particularly veterans whose disabilities are related to wartime injuries. In a simulation during the community consultation where participants were asked to choose the one candidate they would support out of five persons with disabilities for the only remaining bed in a hospital, the war veteran amputee was chosen most often.

There may be a "hierarchy of prejudice" based on the types of health conditions and impairments. For example, amputees, especially veterans, are seen as most able to participate in community life and least stigmatized. People living with visual or hearing impairments are considered as less able to contribute than amputees but more capable than people living with psychosocial disabilities.[40] Psychosocial disabilities are also the least understood among community members, indicating that prejudice is probably most associated with health conditions that people do not understand and therefore fear. Persons living with epilepsy especially experience severe discrimination compared to other health conditions, because many people find episodes of seizures frightening and believe that the health condition could be contagious.

> *"Most of the time [the discrimination is targeted to] the ones who can't control themselves, and they have to be tied or caged."*
>
> — *FGD, Man without disabilities, Savannakhet.*

3.4.4. Teasing and stigma disempower persons with disabilities

Over time, teasing and stigma can negatively affect the self-esteem, confidence, and self-worth of persons with disabilities. This can have a far-reaching impact, affecting individuals' access to education and work, as well as their interest and willingness to engage in social events and activities. Self-stigmatization was also described by one man living with intellectual disability who said he did not go, and did not want to go, to school because he was "stupid."

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[40] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 80

A woman with disabilities explained she had been to a village meeting before, but did not feel confident when she was there.

> *"Although I wanted to speak, I wasn't brave enough because I was scared, I might say something wrong," she said.*
>
> — *FGD, Woman living with hearing impairment, Savannakhet.*[41]

3.4.5. Teasing and stigma lead to social exclusion

Persons with disabilities are less likely to participate in social events with friends or family than persons without disabilities. They are also less likely to feel that they socialize with friends and family as much as they would like.[42] The more severe the impairment, the more likely the person with disabilities would avoid or withdraw from social interaction.

Community members generally say that they would not exclude persons with disabilities. However, most people feel that the decision to participate or not rests solely with persons with disabilities, and do not see any responsibility on the community to be more welcoming or helpful.

> *"[People with disabilities do not normally attend festivals] because, firstly, it's difficult for them to travel. Secondly, because of their disabilities they can't really enjoy the festival, such as eating and drinking like other people."*
>
> — *FGD, Male caregiver, Xieng Khouang.*[43]

Even if they do attend, the widespread view among persons without disabilities is that their participation should come from their initiative:

> *"If they [people with disabilities] go to events, we tend to give them separate food on their own. If they want to eat dessert, we would also give this to them separately and ask them to sit somewhere else. But if they wanted to join us, we would not have any objections."*
>
> — *FGD, Female community member without disability, Xieng Khouang.*

While about three quarters of people in Xayphouthong and Kham Districts said they know a person with disability in their village, about 40% of people in Xayphouthong District and 20%

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[41] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 81
[42] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p.73
[43] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 61

of people in Kham District said they never interacted with people with disabilities whom they know. Less than 10% of people said they were friends with a person with a disability.

The combination of preconceived ideas about persons with disabilities, disempowering social stigma and a high burden of responsibility placed on persons with disabilities to take action if they want to be included can further lead to withdrawal, stigma against self, and exclusion.

3.4.6. Stigma extends to caregivers and families

The stigma attached to disability and its disempowering effects touch not only the person with a disability but also their caregivers and families. Parents of children with disabilities describe others looking at them with disgust or pity when they walk around with their children.[44] In one extreme case, villagers refused to visit a noodle shop owned by a woman whose son had severe difficulties in functioning, because they thought it would bring them bad luck.[45]

Recommendation: Increase understanding and empathy on issues faced by persons with disabilities and showcase stories that illustrate human diversity and demonstrate supportive behavior that promotes inclusion within communities.

3.5. Caregiving places a disproportionate burden on some family members

An activity only begins to feel like a burden when it stretches the family's capacity to fulfill the normal roles and responsibilities of daily life. To understand why caring for a person with disabilities can sometimes feel like a burden to the family caregiver, it is useful to ask: *What are Lao families like? What is their structure and what are the necessary roles and responsibilities of their members?*

Lao people live in extended families: Typically, Lao people live in large, close-knit families that often include three generations living together in the same household.[46] Great respect is given to parents and elders, who may include grandparents, siblings and other relatives. The oldest male, as the family's patriarch, will generally represent the household at village meetings.

The average household has six to eight members. Sometimes two or more families may farm together and store grain in a shared granary. Lowland Lao households average between six and eight persons but may reach twelve or more members in some cases.

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[44] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 81
[45] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 80
[46] Facts and Details, Families, Men and Women in Laos, May 2014
  http://factsanddetails.com/southeast-asia/Laos/sub5_3b/entry-2954.html

There are many daily duties of the household and they are traditionally shared among members: Though both sexes may cut and carry firewood, women and girls are usually responsible for cooking, carrying water, maintaining the household, cultivating kitchen gardens and taking care of small domestic animals. They are also the primary caretakers of small children.

Men predominantly look after larger animals such as buffalo and oxen, hunting, ploughing paddy fields, and clearing slash and burn fields. Both men and women plant, harvest, thresh, carry rice, and work in gardens.

Many women earn a living as small-time traders or vendors, which can require them to be outside their homes at certain times.

Women are the main marketers of surplus household food and other small production such as vegetables, fruit, fish, poultry, and basic household dry goods, while men sell cattle, buffalo, or pigs, and are responsible for the purchase of any mechanical items. Intra-family decision-making is often driven by discussions between husband and wife although men are usually the main decision-makers when selling bigger assets or making large expenditures.[47]

Grandparents often raise children whose parents are away in the fields or at work: When a couple has children, the stay-at-home parents or grandparents will often play key roles in caring for the children until they reach school-going age. Grown-up children frequently live with their parents until they get married and sometimes even after they have their own children, knowing that the grandparents will help raise their children until they have saved enough money to build their own house. The roles of grandparents may vary where older women still work on the farm and do more household chores whereas older men are involved in educating the children and have more opportunities to relax.

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[47] Women's invisible burden: The struggle for dignified and meaningful livelihoods in the informal sector in Lao PDR,

3.5.1. The role of caregiver is decided based on who is available at home

Ethnicity and household composition can influence who is available at home to care for a person with disabilities. For example, it is customary for the youngest daughter in big families to live with the parents, inherit the main house, and become the main caregiver of ageing parents even after marriage. Among ethnic groups such as the Hmong and the Khmou, the family name and property are passed on from father to son. Daughters generally do not inherit any land from their parents and are expected to leave the house and get married to stay with their husband.[48] In Hmong culture, the main caregivers in a house would be women and girls, whose duties include household chores. Men are recognized as the head of the household and will lead traditional ceremonies and community works, as well as decide on all family planning and activities.

In this setting, a child with disabilities would probably be in the care of its grandparents during its early years. Since education for children with disabilities is not often seen as a priority by parents, the grandparents may end up caring for them throughout their childhood, and into adulthood.

3.5.2. The feeling of burden varies based on the level of care needed

A person with a lot of difficulties in functioning such as hearing or seeing can still participate in household duties. However, when a person is fully dependent on a caregiver due to being unable to perform ('cannot do at all' in Washington Group Questions rating scale) in more than one functional area such as mobility, cognition or self-care, the type and amount of care, and skills needed by the caregiver to provide the care significantly increases. This could be compounded when the caregiver, for example, if grandparents also have difficulties in functioning due to age, frailty or illness. If one member of the family is designated as a caregiver for the person with disabilities, children, and/or older family members, it may negatively affect their physical and mental well-being, independence, personal growth and development, since their duties will take up the bulk of their time.

In many such cases, when a person with disabilities is dependent on continuous care, they may be perceived as dependent and as a burden,[49] as the level of care required limits the time and availability of the caregiver to work and participate in day-to-day life, including work and social activities. This could lead to resentment and tension within the family regarding who should stay home to provide care to the person with disabilities.[50]

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[48] Lao PDR: Country Gender profile, March 2006, p.22
[49] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 65
[50] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 31

> *"Our relatives may visit us once in a blue moon. But we have to provide care every day [to the respondent's father]. They [the relatives] don't come because they have already assigned that burden to us."*

> — *Male caregiver, Savannakhet.*[51]

3.5.3. Having a person with disabilities in the family can reduce income by raising the costs of health care

The poor health and increased healthcare needs of some persons with disabilities, especially those with severe difficulties in functioning, can create a financial burden in the form of out-of-pocket payouts for health expenses.

Lack of comprehensive and accurate knowledge about disabilities and general health can lead families to continue seeking a cure even after the doctor has explained that the health condition is not curable. Many families are unwilling to accept such an answer and will spend more time and money seeking treatment elsewhere. Those who can afford it may even seek treatment abroad, while those who cannot turn to spiritual or shamanistic solutions.

Caregivers dealing with persons with disabilities who require a high and continuous level of care often experience personal challenges. The combination of emotional and physical exhaustion from caregiving, combined with the frustration of being unable to work, earn an income, participate in social activities or community life, take a break from caregiving or travel can have a negative impact on the caregiver's physical and mental health, and overall well-being. This can lead to arguments and disruptions within the family and deteriorating family relationships and dynamics.

> *"There are several impacts [of being a caregiver]. I can't do jobs, such as trading, which require me to go to other places. Because if I leave my house for one or two days I would be so worried about things at home and especially about my disabled daughter."*

> — *FGD, Male caregiver, Xieng Khouang.*

3.5.4. Persons with disabilities who recognize they are perceived as burdens suffer from low self-esteem and self-confidence

Knowing that they are dependent on a caregiver even for basic day to day life activities can lead a person with a disability to perceive themselves as a burden to their families. If they also have limited opportunities to leave home and interact with the community, these feelings may cause low self-worth and lack of confidence, shame, self-stigmatization, self-exclusion, and loss of a sense of purpose or desire to change their lives. For children with disabilities who

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[51] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 65

do not go to school and lack literacy and social skills, these feelings may continue throughout childhood and into adult life.

> "People said that since I had polio why did I want to get married, your partner will leave you as you are their burden [...] Some said if my husband left how would I look after my children on my own. They said I might end up crawling with my child on my back begging. I felt hopeless when people said that to me."
>
> — Woman living with physical impairment, Sekong Province.

> "I have mobility impairment, so I am dependent on my friend to help me go to places like toilet, or restaurant for lunch. I almost quit my school because of my classmate's attitude, but what hurt the most was when my close friend said that I was born to be a burden of people around me. From that moment, that word stuck in my head and made me feel like staying at home and not do anything. I even wanted to quit school."
>
> — Woman with physical impairment, Vientiane.

> "Persons with disabilities who can't go [out of the home] by themselves without help or an assistive product may feel they would be a burden to their families or friends if they socialized or went to community events."[52]
>
> — Male, District Labor and Social Welfare Office, Savannakhet.

3.5.5. The community's negative attitudes towards persons with disabilities can extend to their caregivers, and affect their reputation and social interactions

Persons with disabilities and their caregivers are often advised to stay home and avoid participation in village festivals and meetings. In some places, there is a superstitious community perception that people with disabilities bring misfortune and bad luck and are better avoided. This leads to deliberate social exclusion of persons with disabilities as well as their families and caregivers. It is assumed that if the person with the disability brings bad luck, so would their family members, through association. In effect, the stigma is extended to caregivers as well as families of persons with disabilities. There are cases of people avoiding the shops of people known to have a person with a disability in their families, and people in the community not wanting to socialize and interact with them or their family. This attitude can reduce the livelihood opportunities of the person with disabilities and the family.

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[52] CBID FGD transcript: CBID Demonstration Model Assessment – Baseline Survey Report (2020).

"I used to train a person with a disability on how to take care of their animal (in different project). We did a study visit to a village near the training place[…] Villagers reacted negatively when they see the person with disability. Everyone in the village was notified that they should keep their animals away from the person with disabilities because they may get some disease from them."

— *Male CBID worker, Savannakhet.*

"There was one family where I'm from, the son has severe disabilities, and his mother opened a noodle shop. But very few customers visited her shop. They were afraid that they would get bad luck from interacting with that family."

— *Male without disabilities, Savannakhet.*

Recommendation: Increase community perceptions and understanding of disability by reflecting on myths and superstitions and involving village authorities, monks, and teachers in community dialogues about the needs of caregivers and ways to support them while supporting persons with disabilities to access rehabilitation, assistive products, and house accessibility modifications.

3.6. The family plays a key role in positive and negative outcomes for persons with disabilities

Within the family, parents are considered influential in laying the foundations of their children's lives. Their primary role is to provide safety and love, demonstrate and share good values, and empower with compassion and understanding. However, parents display different parenting styles, especially with children who have disabilities. Different parenting styles can have both positive and negative impacts on a child's life.

3.6.1. Overprotectiveness can limit developmental opportunities and cause social exclusion, when keeping persons with disabilities at home

A parent's natural instinct is to protect and shield their children from negative and harmful situations and experiences. This instinct can manifest as over-protectiveness when raising a child with disabilities. In addition, when the parents themselves have a limited understanding of disability and the real potential of the child, the urge to be overprotective can become sometimes overwhelming. Children learn independence in daily life by mastering new skills through repetition as well as trial and error. Children with disabilities may need more repetition and time than children without disabilities to learn these skills. When overprotective parents complete daily life activities on behalf of their children with disabilities instead of letting them try and learn themselves, they effectively limit the optimal development and functioning in childhood and into adulthood.

With the focus on the person's needs, safety, and security, some families' behaviors unintentionally cause increased dependency and helplessness rather than encouraging independence by, for example, letting them venture out alone to play or to do tasks without help or limited support. They may decide not to send a child to school for fear that they might be teased, mocked or bullied and not able to protect themselves.

> *"We only allow her to stay around the house area and help me in my grocery store. It is risky for her to go somewhere by herself. I am scared someone will take advantage of her."*
>
> — *Elder sister of a girl living with intellectual disability, Vientiane.*

> *"When I took my son with autism to walk and play in the park, he ran to one lady with red dress, my child loves red color so he tried to be close to her and constantly play with her dress, but that lady was surprised and shouted to my son and me, "Get off, crazy boy!" […] From my experience, if people in the community understand about autism and could be more open-minded, I believe a lot more parents with autistic children would bring their children to the public/community."*
>
> — *Mother of a child living with autism, Vientiane.*

> *"When the child with disabilities goes to school, they may experience bullying from other friends or someone in school, and that makes them conclude that school is unpleasant. So, their parents might decide not to send them to school."*
>
> — *FGD, CBID worker, Savannakhet.*

Overprotectiveness can be more intense when a person has a mental illness or an intellectual impairment, especially for girls and women. The child or adult is challenged not only by difficulties in functioning, but must also deal with stigma and discrimination, or even emotional or physical abuse, in the community. Concerned about their safety, not confident about how to deliver quality care to them and afraid to leave them unattended, families have been known to lock persons with disabilities in a room at home, and in extreme circumstances in a cage, sometimes chained, to keep them out of social contact and out of harm's way.

> *"It was a tough choice to lock him up in this room. He cannot control himself these days. We do not know what he will do to other people. Only my daughter-in-law, nephew, and I stay home during the day. I love him but it's for his own good."*
>
> — *Mother of a son living with mental illness, Xieng Khouang.*

3.6.2. Rejection of a person with a disability can start at home

Being told that your child is born with an incurable health condition that leads to permanent impairment and lifelong difficulties in functioning can be traumatic for the family, and can cause emotions of shock, anxiety, disbelief, fear, emotional distress, or shame. What had been eagerly anticipated as an event of joy for the family suddenly turns into a lifelong challenge. Some parents, unable to adjust and accept this situation, continue to live in hope that their child will somehow be cured and enjoy a happy and active life.

> *"I am a bit disappointed because I never expected that my child would be born with a disability. I wish they [my child] could be as healthy and complete as others [children without disability], but we don't have a choice."*
>
> *— FGD, Female caregiver, Xieng Khouang.*

Some parents ask "Why our family?" and without a clear understanding of the causes of their child's health condition, they might conclude that they were being punished for their sins or bad luck from their past lives. Depending on the severity of the health condition and related impairment and the parent's ability to cope emotionally and practically with this, some parents may even consider abandoning the child, putting their own concerns and distress before the rights of the child to have a decent and happy life. In some cases, the birth of a child with a disability even leads to separation or divorce as the couple disagrees on how best to cope with the long-term care for their child with a disability.[53]

> *"My neighbor had a baby with a disability and the parents abandoned the baby… I knew another case when the mother took her daughter with disability to live with someone in Thailand. The baby grew up and then married a foreigner and became wealthy. After that the mother came back and wanted a relationship with her daughter, but the daughter said, 'Why do you only think of me now when you abandoned me before?'*
>
> *— Male participant, community consultation, Savannakhet.*

Rejection can also happen when disability occurs later in life due to an injuries or health conditions that cause long-term difficulties in functioning.

3.6.3 When parents and families fully support persons with disabilities, it has a major positive impact

Parents and family members are usually the primary, devoted, frequently unpaid sources of support, assistance and love for persons with disabilities across the life course. Parents and

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[53] Alternative Care in Laos; An exploratory study with children and caregivers, Save the Children, September, 2013 p.20

family members play vital roles as caregivers, educators, teachers, and advocates. As their children grow through adolescence and into adulthood, parents and family continue to provide care, love and a broad range of assistance such as access to education and employment as well as helping them to lead meaningful lives and participate independently in the community. Caring and supportive caregivers and families play a vital role for persons with disabilities to support the achievement of optimal functioning, participation in day-to-day life and overall well-being.

Recommendation: Increase the dialogue between family members, especially mothers, caregivers, and persons with disabilities, to understand and find solutions to the issues they face.

3.7. Education is sometimes deprioritized when financial problems arise

3.7.1. Parents prioritize urgent financial needs over long-term investment in education

When parents have enough money to pay for school uniforms, books, and fees, and do not need their children to help with farm work or the care of younger siblings, sending their children to school is an easy decision. However, when families have little money, they often prioritize urgent household needs over education.[54] The most common reasons parents give for their children not attending or dropping out of school reflect a low perceived value for education ("no interest," "not worth it," etc.) and high perceived cost ("too expensive").[55]

Parents' perceived value of education is lower when it comes to children with disabilities, leading to infrequent attempts to enroll such children and also to reduce school attendance by such children especially after primary school.[56] Children with disabilities are less likely to attend school compared to children without disabilities. In Kham and Xayphouthong Districts, one out of five school-aged children with disabilities have never attended school, while only one out of 20 school-aged children with no disabilities had never attended school in Kham and Xayphouthong Districts.[57]

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[54] Reaching for a Better Life, Community Consultation Workshop,
[55] World Bank, p. 24 http://documents.worldbank.org/curated/en/161641483590757065/pdf/111627-REVISED-PUBLIC-Lao-PDR-Root-Causes-of-Early-School-Leaving-f.pdf
[56] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 32
[57] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 29

"Sometimes people think that there is no need for their children with disabilities to go to school because they think children with disabilities may not use knowledge, so better that they stay at home and do something else."

— FGD, Female community member without disability, Savannakhet.[58]

Persons with disabilities often say a combination of lack of money and lack of ability to learn led them to stop attending school, pointing to a lower value placed on education especially when money is tight.

"I quit school because I lost my eye and I did not learn like my friends did…The reason I left school was that my parents were both very poor. I did not have clothes and could not afford to buy books and pencils at that time."

— FGD, Male with visual impairment, Xieng Khouang.[59]

3.7.2. Parents can be a part of a solution

There is some evidence that women are more likely to support education in the family. Similarly, women were more likely than men to say that children with six out of eight types of impairments should go to school. For instance, 73% of women said that children with learning difficulties should go to school while only 55% of men agreed. Similarly, 39% of women thought that children with mobility impairments should go to school while only 17% of men agreed.[60] Although the data show that mothers are more likely to support education of the children with disabilities, fathers also play a very significant role in supporting the learning of their children.

"I spend 24/7 with my son, and my wife and I try our best to find what he likes. We use that to stimulate him, we stimulate everything that he can do and do it even more… I observed and learned that my son always likes to turn on taps, so I built a lot of water taps around the garden for him to play with it and at the time practicing using his hands and arms. I have learned that he loves music, so I used that to stimulate him to crawl. I never feel ashamed that my son has cerebral palsy, I am proud to say to the public that he is my son and I will never give up."

— Father of son living with cerebral palsy, Vientiane[61]

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[58] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 32
[59] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 31
[60] Handicap International Knowledge Attitudes and Practices (KAP) Survey, 'Linking Disability to Maternal, Newborn and Child Health', February 2012, p. 57
[61] USAID Okard Community Based Inclusive Development Handbook: Diversity and Inclusion, May 2019, p.20

3.7.3. Employers' reluctance to hire persons with disabilities creates a vicious circle by discouraging persons with disabilities from even seeking education or skills in the belief that they will not lead to jobs

Employers see persons with disabilities as less skilled because they often have lower levels of education than others, and thus do not hire them. When families see that persons with disabilities do not get jobs, they are less likely to see the value of sending their children with disabilities to school or to vocational training. Additionally, when persons with disabilities do not have high education or skills, the main jobs left for them, particularly in rural areas, are manual labor, which are ironically the hardest jobs for a person with a disability to adapt to.[62] This further perpetuates the idea that persons with disabilities cannot work, again feeding into the idea that investing in their education is not worthwhile.

Recommendation: Promote dialogue between local education partners and parents in understanding the value and the need for the education of children with disabilities hearing the real success stories from different people with disabilities who are already successful from the education supported sector and succeeding in work opportunities. Build the capacity of teachers in schools and vocational training centers to become knowledgeable resources and change agents on issues related to disability inclusion and social norms.

3.8. There is a dominant focus on what persons with disabilities cannot do rather than their abilities and skills

3.8.1. Community members often define persons with disabilities by their impairment and see them as not capable of contributing to society as much as others

Defining persons with disabilities by their difficulties in functioning goes beyond name-calling, and impacts their overall perception in society and also their potential. While people generally report positive attitudes about accepting persons with disabilities and recognizing their rights, they have more negative views of their capabilities.[63] For instance, roughly one-third of people disagreed with the idea that "persons with disabilities make a positive contribution to this village."[64]

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[62] Community Based Inclusive Development (CBID) Baseline survey workshop, 21 January 2020
[63] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p.76
[64] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 77

3.8.2. When employers define persons with disabilities by what they cannot do rather than their skills and capabilities, it is difficult for persons with disabilities to get jobs

Employers' perceptions of persons with disabilities having limited capabilities is especially detrimental when it comes to employment. While a similar proportion of persons with and without disabilities are working in Lao PDR, persons with disabilities are significantly less likely to have paid work (39.4% vs 10.2%), more likely to be unemployed (14% vs 2.3%) and less likely to be a student (10.7% vs 28.6%) compared to persons without disabilities in the CBID target areas.[65] According to the 2015 Census, women with disabilities faced particular challenges as they were significantly less likely to be employed than men with disabilities (38.1% vs 54.9%), while there was minimal difference between men and women's employment status among persons without disabilities.[66] Persons with disabilities were also more likely to be dissatisfied with their current working status than persons without disabilities.[67]

These disparities are accounted for by the fact that employers often focus only on the limitations of persons with disabilities. Persons with disabilities identify the inability to find or keep a job as a main barrier to their well-being and cite employers' unwillingness to hire persons with disabilities as the main obstacle.[68] Persons with and without disabilities report that employers are unlikely to hire any person with disabilities and especially unlikely to hire anyone with psychosocial disabilities.[69] People generally believe that persons with disabilities can do some tasks like household chores or feeding livestock but both persons with and without disabilities have a difficult time thinking of other jobs that persons with disabilities can do, especially in rural areas.[70]

> *"A person in a wheelchair might have difficulties being employed not just because of their health condition or impairment, but also because there are environmental barriers such as an inaccessible barrier from the employer and colleagues that may underestimate a person in a wheelchair's capacity to perform their task."*
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> — *Woman with physical impairment, Vientiane[71]*

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[65] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 38
[66] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 48
[67] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 47
[68] USAID Okard Activity Baseline Evaluation Report (2019), p. 20
[69] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 32
[70] CBID Demonstration Model Assessment – Baseline Survey Report (2020), p. 50 and Reaching for a Better Life Workshop, January 2020.
[71] USAID Okard Community Based Inclusive Development Handbook: Diversity and Inclusion, May 2019, p.15

Because of lack of awareness and understanding of disabilities and not having past experience with a disability inclusive workforce, employers usually do not focus on skills or tasks that match the functional ability and motivation of the potential hire. A person with a disability is out of the running because of who he is perceived to be rather than what he can or cannot do. Employers also do not consider (or may not know how to consider) adaptations to workstations that could help make persons with disabilities productive.

Recommendation: Increase conversations with employers around the abilities of persons with disabilities and accelerate efforts with families, caregivers, and employers to identify labor and tasks that match the functional ability and motivations of persons with disabilities and discuss possible adaptations of the workstation.

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IV. Rationale for SBCC Strategy Design

In this section, the recommendations from Section 3 are presented in tables grouped into two themes: (1) health and rehabilitation and, (2) disability inclusion, which are connected to seven strategic implications (one is repeated in both themes). These seven strategic implications are discussed in detail following Tables 1 and 2, and are the foundation for the development of the SBCC strategic goals and objectives presented in Section 6.

1. SBCC strategy recommendations related to health and rehabilitation		
Curiosity and inquiry about health conditions and related difficulties in functioning, and available medical and rehabilitation treatment, should be encouraged, enhanced, and sustained. Clear and evidence-based information should be provided to persons with disabilities, family caregivers, and parents to increase their health literacy.	Build capacity of traditional sources such as monks and nuns, shamans, traditional healers, and village authorities to have increased knowledge on health conditions that lead to difficulties in functioning and disability, and available health and rehabilitation services so they can be influenced to recommend medical services alongside traditional practices.	Build capacity of health personnel at all levels of the health system to understand the benefit of rehabilitation medicine including assistive products to improve functioning of the population and increase the prescription and referral to rehabilitation services. At the community level, increase awareness of the population on available rehabilitation services and the benefits.

Strategic implications
1.1. Healthcare providers are an important source of knowledge on health and rehabilitation to improve health literacy and motivate persons with disabilities and families to change health seeking behaviors.   1.2. Local leaders and influencers (monks and nuns, shamans, traditional healers, and village authorities) will play a powerful and cohesive role in helping bring about positive change.   1.3. Persons with disabilities will advocate for their own health.

Table 1 : SBCC Strategy recommendations and strategic implications related to health and rehabilitation

2. SBCC strategy recommendations related to disability inclusion				
Valuing diversity	**Busting myths on disability**	**Empowering families**	**Enabling access to education**	**Enabling access to employment**
Increase understanding and empathy on issues faced by persons with disabilities and showcase stories that illustrate human diversity and demonstrate supportive behavior that promotes inclusion within communities.	Increase community perceptions and understanding of disability by reflecting on myths and superstitions and involving village authorities, monks, and teachers in community dialogues about the needs of caregivers and ways to support them while supporting persons with disabilities to access rehabilitation, assistive products, and house accessibility modifications.	Increase the dialogue between family members, especially mothers, caregivers, and persons with disabilities, to understand and find solutions to the issues they face.	Promote dialogue between local education partners and parents in understanding the value and the need for the education of children with disabilities hearing the real success stories from different people with disabilities who are already successful from the education supported sector and succeeding in work opportunities. Build the capacity of teachers in schools and vocational training centers to become knowledgeable resources and change agents on issues related to disability inclusion and social norms.	Increase conversations with employers around the abilities of persons with disabilities and accelerate efforts with families, caregivers, and employers to identify labor and tasks that match the functional ability and motivations of persons with disabilities and discuss possible adaptations of the workstation.
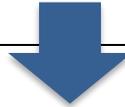
Strategic implications
2.1. Local leaders and influencers (monks and nuns, shamans, traditional healers, and village authorities) will play a powerful and cohesive role in helping bring about positive change. 2.2. Within the family, parents' crucial role in the well-being and development of the person with disabilities from childhood through to adulthood will be strengthened. 2.3. Persons with disabilities and their family members must be the primary advocates of positive changes in all aspects of their lives. 2.4. Teachers play a central role in conversations with different sections of society that convey new knowledge, attitudes, and practices on disability inclusion. 2.5. Persons with disabilities will advocate for their own employment and social inclusion.

Table 2 : SBCC Strategy recommendations and strategic implication related to disability inclusion

4.1. Health care providers are an important source of knowledge on health and rehabilitation to improve health literacy and motivate persons with disabilities and families to change health seeking behaviors (Strategic Implication 1.1)

Well-informed, confident, and competent health care providers will play a key role in referring and persuading people with difficulties in functioning to access and use rehabilitation services and facilitate referral pathways to access services. Competencies in providing quality evidence-based rehabilitation using compassionate communication and a people-centered care approach will enable more meaningful and positive experiences when people with difficulties in functioning and their caregivers use rehabilitation services and lead these service users to informally share stories within their families and the wider community about the benefits in their life.

To build the capacity of health care providers to be well-informed, confident, and competent the following actions will be required:

- Determine the current knowledge, attitudes, and practices of health care providers on rehabilitation to identify current gaps in their understanding of what rehabilitation is. Utilize this data to develop information and advocacy materials on rehabilitation that will promote the importance and benefits of rehabilitation including assistive products that can be disseminated and used by hospital management and health care providers at the Ministry of Health.
- Continued professional development in-service trainings to update health care providers, including doctors, nurses, and physiotherapists, at district, provincial, and central hospitals on rehabilitation interventions to increase the availability of rehabilitation and improve the quality of service and outcomes of functioning.
- Identify and build the capacity of 'rehabilitation champions' within the Ministry of Health, including hospital management and health care providers, especially doctors, who can provide leadership and motivation for doctors, nurses, and physiotherapists to promote and provide quality rehabilitation services at the different types and levels of health facilities.
- Develop role model rehabilitation units at different levels of the health system, including primary health care, to demonstrate and promote to other health care managers and providers the effectiveness of rehabilitation on prevention of disabling complications and optimizing functioning. Animate and facilitate a network for health professionals to share knowledge and successful case stories to promote positive benefits of rehabilitation for all.

4.2. Local leaders and influencers will play a powerful and cohesive role in helping bring about positive change (Strategic Implication 1.2 and 2.1)

Local sources, including monks and nuns, shamans and village authorities, are highly respected and influential within the community and can help spearhead social changes once they understand the cause of health conditions that reduce functioning and lead to disability, and the benefits of rehabilitation to optimize functioning.

Addressing gaps in knowledge through capacity building of leaders and influencers can lead them to influence others by supporting and spreading messages that reduce stigma and discrimination, and change attitudes and practices creating an enabling environment for inclusion. The direct intention of capacity building is not to displace existing traditional beliefs, but to introduce new information that would coexist alongside current beliefs. It is expected that some local leaders may change their beliefs, but others would not. However, it is expected that the new information would lead to positive changes in attitudes towards persons with disabilities and concrete actions to support inclusion within the community. Capacity building topics would include:

- Causes of health conditions that lead to difficulties in functioning and the health and rehabilitation interventions including assistive products that can optimize functioning.
- Stories about persons with disabilities, including what they can do and how they participate in everyday life within their communities, to showcase positive examples of the inclusion of persons with disabilities. Impact of teasing, bullying, and other negative behaviors and how advocacy and specific strategies can address these situations

4.3. Persons with disabilities will advocate for their own health, employment, and social inclusion (Strategic Implication 1.3 and 2.5)

Empowerment is a precondition of advocacy, while also a consequence of advocacy in action. Empowerment creates and builds capacity in a person to advocate for their needs, but this needs practice to master through learning by doing. The exercise of advocacy also builds capacity to be empowered, therefore, one supports the other in a cycle of learning by doing. Acts of advocacy create experiences that become teachable moments that further the empowerment of a person, family, or collective.[72]

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[72] Empowerment in CBR: Towards Community-Based Inclusive Development, https://polhn.wpro.who.int/courses/empowerment-in-cbr

Empowerment needs to begin at the individual level where the person with disabilities has a voice to speak out for themselves and builds their personal capacity to effectively advocate for themselves related to affect actions, thoughts, and relationships.

Affect (emotions)	Actions (behavior)
• Feeling hopeful • Having a strong sense of self worth • Having confidence, you can achieve something even if difficult • Feeling you have skills to self-advocate	• Self-directed behavior • Ability to communicate • Ability to do the task and sustain effort that could mean use of assistive product to help the person with disabilities • Resilience
Thoughts (cognitions)	**Relationships with others**
• Thinking processes that create, adapt and monitor advocacy efforts • Ability to analyze, plan, adapt, and learn	• Holding close relationships with others • Work collaboratively • Nurture connections • Resolve conflicts • Negotiate

Table 3: Model of Individual Empowerment.[73]

Individual empowerment grows through the support of family and friends (i.e., social empowerment). Family and kinship can shape actions in powerful ways through interdependency, being emotional connected, and feeling loved and cared for. This interdependency within the family unit or from friendships creates strength so the person with disabilities feels stronger to act knowing someone is there if they need help and enabling them to be braver. This is also reinforced if the person with disabilities and family knows the community supports them.

By increasing the person with disabilities knowledge, focusing on their abilities and strengths, building self-esteem and confidence, creating a supportive network with like-minded people (family, friends, self-help groups, or the wider community), this will enable them to feel, think, and act with the support of others to advocate for their needs related to health,

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[73] Empowerment in CBR: Towards Community-Based Inclusive Development, https://polhn.wpro.who.int/courses/empowerment-in-cbr

employment, and social inclusion. Persons with disabilities and their families will make their own decisions and take responsibility for changing and improving their lives.

- **What changes and activities need to happen to empower them:** To help persons with disabilities cope with their challenges, they need a support network to help boost their self-esteem and confidence. Being around like-minded people will empower them to take control of their lives.

   Persons with disabilities also need to increase their knowledge by focusing on their strengths, not their weaknesses, and things they are capable of doing. They can attend workshops, training sessions or social clubs to help in updating their skills. The most important part is to keep sending positive messaging about individuals' worth and potential, and encourage them to always ask for help from their family, friends, and community, because all people need assistance to achieve their goals.

   " *I love weaving. Although I do not have two hands, I have abilities and perseverance like others.* "

   - Ms. Phanh, USAID Okard Beneficiary

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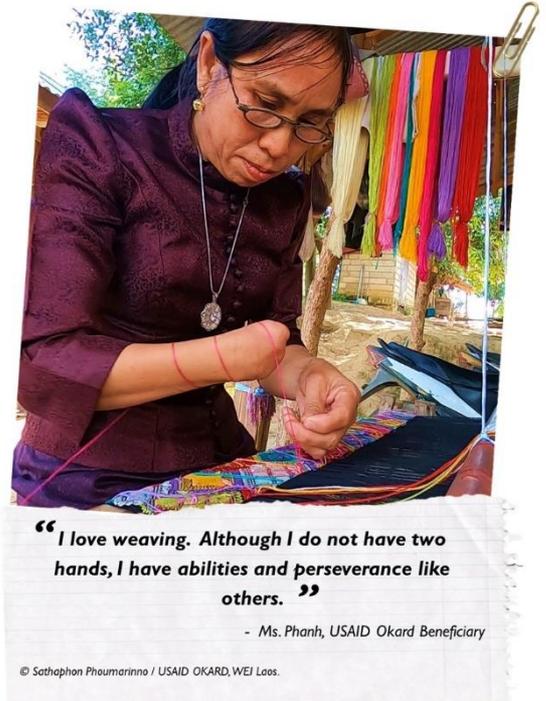
- **What changes could be driven by persons with disabilities:** It is essential for persons with disabilities to find ways to minimize the impact of disability on their lives, through commitment, willingness, and creativity to do things differently. Although they have limitations due to their difficulties in functioning, they can reduce the impact of disability on their lives and become a driving force to help reduce stigma through leadership and advocacy. For example, a person with disabilities acting as a role model may show an employer that persons with disabilities have the ability to do specific types of work and participate in social activities on an equal basis with others. Through acting as a role model for inclusion, one individual can help other persons with disabilities to overcome internalized stigma and change negative perceptions that may exist within communities.

4.4. Within the family, parents' crucial role in the well-being and development of the person with disabilities from childhood through to adulthood will be strengthened. (Strategic Implication 2.2)

Parents play a crucial role to support their child's growth and development and their level of engagement and relationship with their child has a major influence on the outcome. Parents undertake multiple responsibilities and play influential roles when caring for their child from birth throughout childhood, and for persons with disabilities, often extending into adulthood. These include:

- **Monitoring childhood developmental markers and recognizing health conditions sometimes that are not visible that may lead to disability:** Poor knowledge of childhood developmental markers and signs of health conditions may currently deter this, but parents with clear knowledge of what to expect and look for as their child grows are more likely to notice difficulties in functioning earlier.

- **Parents are more likely to take informed health care decisions to seek the necessary and appropriate healthcare for their child:** When parents lack knowledge and are only familiar with local and traditional remedies from the local shaman, fortune teller or traditional healer they are more likely to go to local sources for cures rather than seek healthcare and rehabilitation to improve function and quality of life. With more information and improved knowledge, parents can make more informed decisions for their child and increase the likelihood of them choosing healthcare and rehabilitation services rather than traditional remedies resulting in positive outcomes for health, function and overall child development.

- **Parents, especially mothers, play a crucial role to emotionally support their child:** If a child is being bullied, teased or gets hurts, the emotional response of parents in these situations is to protect and emotionally comfort them. These emotional responses are natural as they want their child to be valued. When parents have a strong understanding and empathy concerning issues faced by their child especially bullying, they can effectively advocate for their child rather than being overprotective. Finding ways to help their child deal with difficult and challenging situations and engage other family and community members to support the child will ultimately increase the child's confidence, social engagement, and participation.

4.5. Persons with disabilities and their family members must be the primary advocates of positive changes in all aspects of their lives (Strategic Implication 2.3)

Beliefs and attitudes on disability and the resulting social expression of these often originate within the family setting. Therefore, change at any other level within society, whether at village, district, provincial, or central level from different stakeholders, is inconceivable without discussion and change within the family.

The Social Ecological Model shows us that a person (the innermost 'Self' circle) has the most immediate connection with partners, family and peers ('Interpersonal' circle), and that they are the most
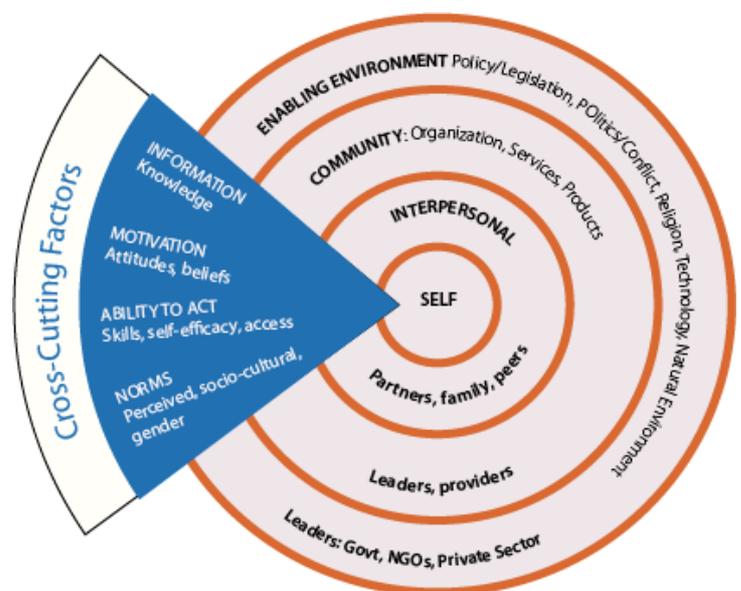
influential. Persons with disabilities have most direct contact with, support from, and are influenced by their immediate family members. Within the family structure, the person with disabilities may have the strongest connection with their main caregiver.

Lao people typically socialize as families, and most family infrastructure includes three or sometimes more generations sharing one house or compound. Therefore, families are usually diverse with different ages, gender, education, roles, and responsibilities, whether working outside the home or stay-at-home to complete caring and household tasks. Roles vary in terms of leadership, decision making, and sources of knowledge. Parents are expected to lead and make decisions while grandparents are well respected and mature sources of knowledge that provide stability for their children and grandchildren. Children's opinions will be considered by parents and allowed based on their decisions, so children are expected to follow the leadership of their parents. This family ecosystem with established roles is crucial for a healthy, functioning family that deals with day-to-day life. Parents and other family members ultimately play a vital role as caregivers, teachers, and advocates to support the person with disabilities.

For discussion and change to be achieved within families so they can advocate for positive change in their lives, several things are needed: improved knowledge and understanding of health, functioning, and disability; identification and reduction of stigmatizing attitudes and behaviors; recognition of the potential of persons with disabilities; and support for their abilities to contribute to society. This may include having access to accurate information on causes of health conditions that reduce functioning and lead to disability, awareness of developmental markers of childhood, early identification and rehabilitation, and assistive products to optimize functioning. Families may also be directly influenced and supported by community figures such as village authorities, monks and nuns, shamans, traditional healers, and other community members, as illustrated in the Social-Ecological Model within the 'community' circle.

When family members recognize the potential of persons with disabilities, this transformation in perspective can result in the family supporting the person with disabilities, and together they can advocate and take action to access education, employment, and participate and contribute to community life.

Each family member also plays a social or community role in their daily occupations, whether they are a doctor, nurse, employee, employer, teacher, farmer, healthcare provider, student and beyond. As changes start from within their family, this will diffuse into the larger community through their interactions with others.

4.6. Education authorities, school management and teachers play a central role in conversations to convey new knowledge, attitudes, and practices on disability inclusive education (Strategic Implication 2.4)

Local education authorities, school principals, and teachers play a key role in promoting the value of education with parents and the wider community, and the need for all students, including students with disabilities, to participate in education. Teachers play a specific and important role in shaping the ideas and behavior of students by increasing their knowledge on specific topics and issues that they can bring home and share with their families. Moreover, teachers can address issues related to teasing, bullying, and discrimination among students in the classroom by role modeling positive attitudes, sharing knowledge to change attitudes and behaviors, and encourage peer-to-peer support by actively engaging the whole class and activating school buddy systems to create an inclusive environment.

Addressing knowledge gaps on disability inclusive education, diversity, and disability inclusion within society through training is crucial in order for local education authorities, school management, and teachers to understand, accept, and respect students with disabilities, and actively include them in the learning process within the classroom, whether at primary or secondary schools, Technical and Vocational Education and Training (TVET) institutions or at Universities. USAID Okard activities will focus interventions related to TVET education, while the CBID Demonstration Model will include engagement with local education authorities and teachers at primary and secondary school levels, dependent on the children receiving CBID case management.

**GOALS &
OBJECTIVES**

V. Strategy Goals and Objectives

The SBCC strategy has two key strategic goals and six objectives to address the SBCC recommendations:

Strategic Goals

- Goal 1. Improve understanding on disability at all levels of society in order to reduce stigma and discrimination towards persons with disabilities, while increasing social inclusion, access, and utilization of health services and access and participation in employment.
- Goal 2. Improve understanding on what rehabilitation is, including information on assistive products, and the benefits of rehabilitation to optimize functioning and reduce disabilities for persons with health conditions and thus contribute to increasing the demand for and use of rehabilitation services.

Six objectives have been designed to support the achievement of the SBCC goals:

Goal 1: Improve understanding of disability at all levels of society in order to reduce stigma and discrimination towards persons with disabilities, while increasing social inclusion, access, and utilization of health services and access and participation in employment

- Objective 1.1: Reduce stigmatizing attitudes and behavior towards persons with disabilities within families and the wider community.
- Objective 1.2: Raise awareness of the skills, ability, and potential of persons with disabilities to work and contribute positively to their community.
- Objective 1.3: Sensitize family members to recognize and support the potential of persons with disabilities.
- Objective 1.4: Increase the confidence of persons with disabilities to engage more actively in society.

Goal 2: Improve understanding on what rehabilitation is, including information on assistive products, and the benefits of rehabilitation to optimize functioning and reduce disability for persons with health conditions and thus contribute to increasing the demand for and use of rehabilitation services

- Objective 2.1: Increase knowledge of health service providers, including traditional sources, at all levels of the health system about the definition and scope of rehabilitation and its benefits.
- Objective 2.2: Increase knowledge of community members on health conditions and related difficulties in functioning, and the available medical and rehabilitation services available through providing clear and evidence-based information materials and sources.

" I am extremely grateful and excited at the same time for my daughter to receive the walking frame and special wheelchair. This will help her to sit independently and to move around easily and be able to play with her friends. As a father and the main caregiver, I will strictly follow the instructions from the doctor on how to take care of my daughter's health condition as well as making the great use of the provided assistive products " – Father of USAID Okard Beneficiary

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STRATEGIC APPROACHES

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VI. SBCC Strategic Approaches

Based on the research findings and recommendations (Section 2), and the strategic implications (Section 3), this SBCC Strategy and Action Plan has been designed and called *"Reaching for a Better Life (RBL)."* The title of the SBCC Strategy and Action Plan intentionally does not include the word 'disability' in recognition that creating a more inclusive environment for persons with disabilities calls for action across a spectrum of community players and aims to improve the quality of life not just for persons with disabilities, but also their families and the broader community.

The design of the SBCC Strategy and Action Plan is based on the following approaches to drive action and behavior change in communities to create inclusive environments for persons with disabilities:

1. Improve the quality of inquiry about disability and rehabilitation.
2. Magnify and showcase role models of successful change.
3. Use communication that is interactive and invites responses.
4. Interlink media and processes to increase synergies between interventions.
5. Base communication on dialogue rather than direct dissemination.

6.1. Improve the quality of inquiry about disabilities and rehabilitation

The SBCC approach is strongly based on ownership of knowledge by its recipients. Research has demonstrated that knowledge that is not sought is not retained and that unilateral messaging is less persuasive and impactful than knowledge and behavior acquired through interpersonal dialogue processes.

Methodologies used in this strategy and action plan, to increase knowledge and understanding of families and communities about disability and rehabilitation, will be built upon increasing the desire to know more. This involves improving the quality and quantity of participating audiences to ask better questions and increase their need for more detailed and credible information about health conditions and disability to guide their health care choices. Methods that can help improve the quality of inquiry include discussion groups, serial drama, social media campaigns, street theatre, and smartphone quizzes among others. Specific methods will be selected and built into every SBCC intervention as appropriate for the context.

Questions will be harvested from audiences after activities and used to evaluate areas of curiosity, concerns, emerging information needs, and success stories. The harvesting and analysis of questions will be a key feature of all interventions. When knowledge is sought in this

way, the answers are received as a response to a community or an audience need and are more likely to be retained and acted upon.

Illustrative example of inquiry during a discussion group

The fortnightly meeting of caregivers and parents, especially mothers, meet to discuss what a caregiver can do if she finds that her own career, income, and quality of life is being affected by the responsibilities of all-day caregiving. The discussion is conducted in the form of a Figureheads[74] role-play session, in which a person role-playing the caregiver presents her dilemma and the 'community' gives advice and suggestions, which are then debated.

At the end of the session, the facilitator will ask discussion group participants to write down any new questions they have on a piece of paper with or without their names and put them in a box as they leave. This is known as harvesting questions. The questions will be analyzed locally and used to design future sessions, and to identify emerging concerns and areas of low understanding. The results will be shared back with the sub-recipients to help them design and plan future discussion groups.

6.2. Magnify and showcase role models of successful change

Changes in norms and behavior towards persons with disabilities are expected to emerge from iterative and immersive interventions such as discussion groups, storytelling, online discussions, and others. People who embody desired attitudes and behaviors, referred to as role models, are expected to already exist within the community and are expected to emerge as a result of the interventions.

Previous SBCC experience has shown that a community member who models new behavior and actions, and can explain why, is far more credible and influential than messages developed by a project that promote those same behaviors and actions.

Magnifying role models' behavior or stories of successful change across the project from the different interventions will be a catalyst and motivation for change by not only showcasing the desired behavior but also showing that it is already being practiced. The unscripted and spontaneous personal testimonials of role models will be a powerful motivation for others to

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[74] The Figureheads role-play is a participatory exercise that enables an exploration of complex personal issues related to disability and inclusion. Figureheads works like a slow 'massage' that first moves the group towards introspection and comment about various experiences, and finally brings about a full sharing of personal experiences and observations. The game helps unravel knowledge, attitudes, beliefs, and practices as they exist in their pristine state. Retrieved from Playing the Figurehead Game, C Y Gopinath, Strategic Communication and Advocacy Consultant.

change when testimonials are captured and dispersed, for example, through social media apps, television, radio, and other media.

Sub-recipient team members will be trained to spot precursors of behavior change from the target audience, such as declarations of intention to change or posing of questions about change, and thus identifying role models. Once new behavior or attitudes have been identified, the team members will engage in a deeper discussion with the role model so that their example can energize and motivate the community. A role model will become a project-wide resource, and could be incorporated, with consent, into other activities.

Illustrative example of identifying a role model during a discussion group

During a discussion group exercise when sharing experiences, a business owner that runs a garment shop reveals that they currently employ one person with hearing impairment and recently recruited a second person also living with hearing impairment. They share that they find people with hearing impairments to be good and accurate with sewing buttons on garments and are also very productive as they do not get easily distracted.

The business owner who said this has the potential to become a role model. The discussion group facilitator will engage them in a one-on-one conversation to get more details of the experience. Further exploration could consist of a visit to the factory and interviews with the employees with disabilities to get their account of their experiences.

Once the role model's story has been validated, the facilitator would explain the project's other interventions and goals and ask them if they would be interested in voluntarily sharing their experience with a wider group of people.

Details of the role model will be shared with other sub-recipients and interventions. Examples of methods that will be used to magnify the behavior of the role model includes:

- Recording an interview, the role model and including this within a storytelling video.
- Conducting a live interview with the role model on Facebook.
- During a public meeting, honoring the role model. If possible, media/press persons would be invited to further spread the story.
- Inviting the role model to speak to other employers individually or during group events.
- Creating and displaying posters featuring the role model and highlighting their behavior.
- During other discussion groups inviting the role model to talk and share experiences that demonstrate their positive attitudes and behavior.

6.3. Use communication that is interactive and invites responses

SBCC is more effective when people arrive at their own conclusions and change as a result of discussion and reflection. Therefore, all communication should be interactive and open-ended, i.e., it is response-driven, so inviting an answer or response from the audience, whether viewers, listeners or readers. As a principle, 80-90% of communication should end with a dilemma or a question that seeks a response.

Potential media that can be response-driven includes social media platforms like Facebook, texting platforms like WhatsApp, in addition to traditional and mass media such as TV, newspaper, and print media. The project will choose media types for SBCC interventions based on the context that the target audience can access and the message that needs to delivered. Audiences will be able to respond by posting to online discussions, providing verbal responses during discussion groups, or using WhatsApp groups to share ideas and reflections.

Examples of interactive communication

- A case story is posted on Facebook that shares a "what-if" scenario about a child that has cognitive impairment and whether the caregiver should go to a shaman or a rehabilitation center. The post would be boosted to select audiences, who would be invited to share ideas.
- A storytelling video in which two caregivers are interviewed about supporting a person with disabilities where one uses rehabilitation services to help the person and the other uses a shaman. The video ends with a question to the viewer, asking which support would be better for the person with disabilities. The video would be shared through social media channels, WhatsApp, and other media.

6.4. Interlink media and interventions to increase synergies between interventions

It is important the SBCC strategy exploits and enhances synergies between different sub-recipients and interventions so that content and outcomes of each activity are shared across all of the USAID Okard Activity and influence future discussion, activities, and events. For instance, when a sub-recipient produces storytelling videos using interviews, success stories, predicaments, and dilemmas, it is recognized that topics that could be used to create storytelling videos will likely emerge from other activities such as discussion groups and community activities. Conversely, the effect of storytelling videos will only be optimized if sub-recipients use them within other project interventions, i.e., discussion groups, online discussions, etc.

> **Illustrative example of synergies between SBCC interventions**
>
> During a discussion group, a person with disabilities shares how they have established and managed a small business in their village. This story is shared within the project and another sub-recipient decides to showcase this in a storytelling video they are creating. The storytelling video is used in communities to inspire viewers. It is used to animate a discussion group session to expose deeper issues and barriers, as well as inspire some of the participants to try something similar themselves. The same video is aired on Facebook to reach a different audience and stimulate Facebook comments and discussions.

6.5. Base communication on dialogue rather than direct dissemination

A 'seek-and-find-and-own' approach to knowledge and change is strongly endorsed within the SBCC strategy. While the SBCC strategy has clear and specific recommendations about the knowledge, attitudes, and behavior changes sought to support disability inclusion, the catalyst for those changes is expected to emerge from the audiences as their level of involvement in questioning, reflection, and understanding deepens.

For this to happen effectively, sub-recipient team members will be taught and encouraged not to promote, push, or disseminate call-to-action messages directly, such as "take this person with difficulties in functioning to a rehabilitation center rather than a shaman" or "what a person with a disability can do might surprise you." Instead they will be trained to use probing questions and "what-if" scenarios that challenge and stimulate the target audience to explore and reflect, which results in a dialogue driven by questions and cross-questions. The expected result of dialogues between participants, audiences, and communities over time will be different consensuses and actions emerging and converging reflecting change in knowledge and behavior.

While the discussion group facilitators will focus on a 'seek-and-find-and-own' approach they will also directly share accurate information on topics being explored by target audiences. However, the facilitator will first gain 'permission' to share correct information if competing conclusions emerge over time during discussions, and it is clear that people do not know which one to believe. For example, one group may feel strongly that difficulties in functioning and disability are a karma outcome while another feels it is caused by a health condition that should be addressed by a doctor at a hospital or rehabilitation center. The discussion group facilitator could then invite a doctor and a traditional healer or a shaman to present their points of view to the group. The discussion could also be captured live on a camera phone and become content for a storytelling video that invites viewers to judge who is more convincing, the shaman or the doctor. Messages that emerge from these processes with target audiences will converge towards new perceptions, attitudes, and conclusions. The generated language and arguments will be analyzed and used to create media such as posters, leaflets, and others.

AUDIENCE

MESSAGE FRAMEWORK

VII: Audience and Message Framework

The SBCC strategy will target different audiences at three different levels: primary, secondary, and tertiary.

Primary Audience	Secondary Audience	Tertiary Audience
Persons with disabilities	Teachers	Central government
Caregivers	Village chiefs	Local authorities
Mothers and fathers	Monks and nuns	Social media users
Healthcare providers	Traditional healers	
Youth	Shamans	
Employers	International organizations	
	Businesses	

Table 4: List of SBCC primary, secondary, and tertiary audiences

Primary Audience

The primary audience of the SBCC strategy will be women and men with disabilities, female and male caregivers, mothers and fathers of children with disabilities, health service providers, youth, teachers, and employers. These priority audiences are those where SBCC interventions aim to change or modify their behavior through specific and direct messages.

Secondary Audience

Teachers, village chiefs, monks and nuns, shamans, traditional healers, employers, and international organizations will be addressed as secondary audiences with crucial influence. Therefore, they will support the desired behavior change in the primary, priority audience. For example, religious and village authorities who can influence people in a community, teachers who can influence youth or students in the school, traditional healers and shamans that can influence person with disabilities and caregiver's health seeking behaviors, or employers that can influence the business community about inclusive employment.

Tertiary Audience

The tertiary audiences will include local authorities, social media users, and the central government whose actions indirectly help the behaviors of all other audiences. The tertiary audience's actions reflect the social, cultural, and policy factors that create an enabling environment to sustain the desired behavior change.

The key messages framework that the USAID Okard 'Reaching for a Better Life' SBCC Strategy and Action Plan will utilize includes two sets of messages related firstly to inclusion of persons with disabilities that targets all audiences, and secondly, health and rehabilitation targeting healthcare providers within the primary audience.

Messages related to inclusion of persons with disabilities (for all audiences)
Persons with disabilities refer to 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.
Persons with disabilities are not an object of charity or a burden to be assisted, but somebody with equal rights and dignity that we each respect and aim to empower on an equal basis with all human beings.
A diverse society is a mixture of differences and similarities including individual characteristics, values, beliefs, experiences, backgrounds, and behaviors. Disability is part of human diversity on the continuum of life and the social identities of persons with disabilities should be valued and embraced.
People with disabilities have the same rights as others and deserve to be treated with the same respect and dignity as others.
Inclusion is an effort of all members of the society and practices in which different groups or individuals having different backgrounds are culturally and socially accepted and welcomed, and equally treated.
Inclusion is a sense of belonging that makes people feel respected and valued for who they are as an individual or group.
The process of inclusion engages each individual and makes people feel valued as being essential to all activities in the society and empowers them to access quality education and healthcare, job opportunities, access to assistive products, when needed, access information and communicate with others, and participate in all kinds of social events as much as they can.

Persons with disabilities have the capacity to contribute to society on the same level as others.

Messages related to health and rehabilitation (for healthcare providers)
Rehabilitation is a key health strategy for the entire population addressing the broad needs of people that have difficulties in functioning across the human lifespan, not just for persons with disabilities.
Rehabilitation is a core component of the continuum of healthcare alongside promotive, preventative, curative, and palliative services, and should be considered an essential component of integrated health services at all levels (primary, secondary, and tertiary healthcare).
Rehabilitation is a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.
Rehabilitation is effective in reducing hospital stays, improving health outcomes, and is cost effective.
Assistive products are an essential component of rehabilitation that enable people with difficulties in functioning to perform tasks they would otherwise be unable to do or makes it easier and safer to do. Assistive products should be available at the primary healthcare level.
Early access to rehabilitation interventions (different techniques and exercises) through its integration in primary healthcare helps to prevent complications, optimize outcomes, mitigate disabilities, and improve people's ability to live independent lives.

*Table 5: SBCC messaging framework related to inclusion of persons with disabilities and health and rehabilitation.*

INTERVENTIONS

VIII. Interventions

Specific SBCC interventions have been selected to address changes in knowledge, attitudes, and behavior with five key interventions being used to address SBCC recommendations: discussion groups, storytelling, online discussions, honoring change, and launching awareness raising materials. SBCC interventions will be integrated within the different components of USAID Okard and link with the Gender and Inclusive Development Action Plan (GIDAP).
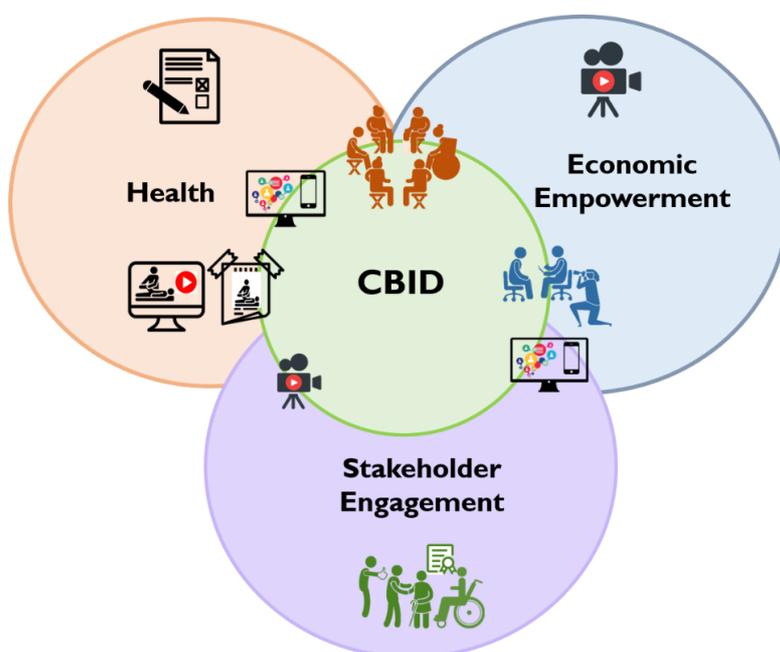
Type of SBCC intervention	Specific Target Audience	Sub-recipient	Targeted SBCC recommendation
Discussion group	Persons with disabilities, mothers and fathers, caregivers (primary audience)	Quality of Life Association (QLA)	Recommendation 1, 3, 6, and 7
Storytelling	Persons with disabilities, mothers and fathers, caregivers (primary audience), teachers, village chiefs (secondary audience), and local authorities (tertiary audience)	Association for Rural Mobilization and Improvement (ARMI)	Recommendation 1, 3, 6, and 7

Storytelling competition	Person with disabilities and youth (primary audience)	Humanity & Inclusion	Recommendation 3
Online Discussions	Persons with disabilities, employers (primary audience), international organizations and businesses (secondary audience), and social media users (tertiary audience)	Disability Advisory Mainstreaming Service (DMAS) Center	Recommendation 4
Honoring Change	Any of the primary, secondary, and tertiary audiences based on circumstances and opportunities	NCDE	Recommendation 3, 4, 6, 7, and 8
Health Discussion Group	Monks, traditional healers (secondary audience)	Department of Healthcare and Rehabilitation (DHR)	Recommendation 2
Launch of awareness raising materials on rehabilitation	Healthcare professionals (primary audience)		Recommendation 5

Table 6: Summarizes each SBCC intervention related to the target audiences, the sub-recipient implementing the intervention and the connection to the SBCC recommendations, with a detailed description of each intervention and the related methods below.

8.1. Discussion Group

Discussion groups will be completed as part of the CBID Demonstration Model community mobilization activities with CBID stakeholders. Discussion groups will have a fixed-size, fixed membership of stakeholders bringing together primary audiences, including persons with disabilities, parents, and caregivers who will meet periodically over several occasions to use dialogue methods to explore issues related to disability, stigma, and social inclusion of persons with disabilities.

Discussion groups will be facilitated by CBID facilitators trained on SBCC interventions and methods. SBCC methods used during the discussion groups will use the Figureheads role-play, experience-sharing, and interviews with role models of change. Discussion groups will be built around the principle of progressive immersion in the details of a topic through the methods listed above. Progressive immersion is expected to improve the quality of inquiry, create greater ownership of the knowledge received, and greater motivation to try new behaviors.

" It doesn't matter that someone was born with disabilities or without disabilities, but what matters the most is the environment that they are living in, that's why we all together need to make an inclusive community where everyone is equal and is able to participate and live independently "

- A participant of the Social Behavior Change Communication (SBCC) group discussion.

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Typically, each discussion group session will involve 15 people and this fixed member group will complete three discussion groups. Each discussion group will last approximately 120 minutes and be scheduled every month. Based on the SBCC methods utilized, especially sharing of real-life stories, it is expected that participants represent a diverse range of social characteristics including gender, age, ethnicity, type of impairment, and education so the intersection of these different social characteristics can be discovered and explored during the discussions. Therefore, participants will be identified and selected based on purposive sampling.

At the end of each discussion group, questions asked by participants will be harvested where new knowledge and further discussion is needed to answer the questions. The different types of questions will be used to plan future topics, and also shared across the project to identify trends, emerging concerns, and consensuses.

8.2. Storytelling

Storytelling is the use of real-life stories that when shared illustrate change and successes about persons with disabilities to cause reflection and generate inspiration. By showcasing stories of change through storytelling, it will spark community dialogues around disability-related issues where change is urgently needed. Stories identified and selected will illustrate challenges, outcomes, solutions, and successes related to persons with disabilities accessing rehabilitation services, engagement in economic participation and social activities within the wider community.

Stories will be showcased by role models and reflect the perspectives of either primary or secondary audiences (as described in Section 7). A role model is defined as an individual that demonstrates authentic and sustained behavior that other community members can and should imitate or demonstrate a solution to a problem that many are facing. Role models may already exist in the community or may emerge as knowledge, attitudes, and behavior changes through the SBCC activities.

- Existing role models who already embody the values and behaviors the project seeks that could transmit and circulate messages within the community;

- Emerging role models, i.e., those that might have participated in discussion groups or have been identified through CBID case management that are starting to demonstrate values and behaviors similar to existing role models

By using the available role models to tell stories to target communities during USAID Okard activities it will magnify messages and serve as an inspiration and a sign to others that change is possible and is already happening.

Potential themes of stories

- Persons with disabilities that have started going to rehabilitation and can describe what happened and what impact it has had on ability to complete day to day activities.
- Employers who have decided to employ persons with disabilities that can share the potential abilities of persons with disabilities and how they have supported their inclusion within the workplace.
- Persons with disabilities who have started taking part in social life within the village who can share how this has made them feel and the reaction of the community.
- Persons who share examples of teasing and bullying, why it is not appropriate behavior and ideas of how to deal with these negative behaviors within the community.
- Monks, nuns, or shamans that can explain the medical perspective of health conditions that cause difficulties in functioning and benefits of healthcare and rehabilitation alongside their own traditional beliefs.

- A self-employed person with disability that can share their experiences of starting and managing a small business in their local community.
- A mother or caregiver who can explain how their experiences of caring for a child with disabilities and what action they took when concerned about delayed development milestones.

It is assumed that from active community searches some stories will already exist within the community while others will emerge from interaction with families receiving case management, with community members, or other stakeholders. Storytelling will include a mix of existing stories and those that emerge during project activities. Stories may emerge during discussion groups or online discussions on social media, for example, when someone responds to a dilemma by sharing their personal experience or reaching out to village authorities that may know stories from their communities.

Stories will be presented in different formats including interviews presented in video- or audio-only formats, printed leaflets, or posters that will be shared primarily on social media platforms (Facebook and WhatsApp).

8.3. Online Discussion

Online discussions refer to a stimulated discussion in which participants discuss specific predicaments or dilemmas related to disability and offer perspectives, solutions, and examples. The online discussion would be triggered by a post in which a person seeks help for solving a predicament or dilemma. For example, an employer could post a dilemma related to employing a person with disabilities:

> *I run a garment factory and feel that I could easily use blind workers for sewing buttons on the garments or packing them. However, I am afraid that I will end up incurring extra medical and administrative costs in order to create a factory environment suitable for blind people or for dealing with potential accidents that may occur as they cannot see. I cannot afford such costs although I do think that some of the garment production can be done by persons with disabilities.*

Online discussions will be driven by moderated Facebook posts, and boosted to reach specific audiences. For example, the above post would be shared on Facebook, and target business owners and members of the blind community (blind persons, family members, other people with experience working with blind people) who would engage in the discussion to offer their perspective and potential solutions. Online participants will post answers based on their ideas or direct experience, pose new questions to find out more information, share documents, pictures, and videos that illustrate real stories of blind persons employed in the workforce. The same post would be magnified through other social media platforms, for example, Instagram or WhatsApp, which would link people to the original Facebook post.

It is expected that real-life dilemmas and predicaments around disability, rehabilitation, economic empowerment, and social inclusion, and other topics will emerge from community discussion groups and responses from storytelling. They will be captured on feedback forms and analyzed to create lists of dilemmas and predicaments that will be shared with the USAID Okard team and sub-recipients as a resource that can be adapted and used for online discussions.

Anonymous online moderators would monitor the online discussion and stimulate the conversation by asking questions to provoke the participants. The moderator would have control of the online discussion to manage inappropriate or irrelevant content, promotions, and misbehavior, such as trolling. The moderator will be alerted to participants who seem particularly engaged with the topic and will initiate one-on-one contact with them, either online or offline. Over time, this will increase participation, stories of change, and engagement.

It is important to note that online discussions will not be directly linked to a project, NGO, or other institutional entity because in order to evoke a genuine response, it should be perceived as spontaneous and real. To this end, such posts will not be linked to USAID Okard marking and branding.

8.4. Honoring Change

Behavior change theories list intention to change as an important step towards actual change and to reinforce this 'honoring change' will be an intervention used by government and village authorities. Honoring change is an activity where public recognition acknowledges and applauds those that commit to change their behavior and those that fulfil the commitment. Commitments would be honored publicly, either by government leaders from NCDE, Ministry of Labour and Social Welfare, Department of Healthcare and Rehabilitation, Ministry of Health, and by village authorities. Examples of commitments and acts honored includes:

- Honoring a business owner that employs persons with disabilities.
- Honoring a parent that commits to a full-time education for their children with disabilities and acts by taking their child to school every day.
- Honoring a teacher that supports a student with disabilities in their classroom.
- Honoring health care staff or a health facility that makes progress towards improving services for persons with disabilities.
- Village authorities honoring a community member during a village celebration for their efforts to support a person with disabilities and promote an inclusive village.

MONITORING

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IX. Monitoring

To measure the achievement of the SBCC strategy goals, objectives, and track the planned interventions, data will be collected from multiple sources and analyzed to determine the changes that have occurred.

An evaluation report will be written by the SBCC Coordinator at the end of the USAID Okard project after all interventions and analyses are completed. The report will evaluate the SBCC strategy by presenting the analysis methods and consolidated data results indicating what changes have occurred, what has not changed, lessons learned during the implementation of SBCC, and recommendations for the future.

9.1. Outcome measurement (Goals and Objectives)

To measure change related to the goals and objectives of the SBCC strategy, three main data sources will be utilized: the CBID Demonstration Model Assessment–Endline report, CBID Case Management database, and USAID Okard Performance Evaluation Endline. These assessments and databases are independent of the SBCC interventions, but contain rich and useful data linking to the SBCC objectives (either in the reports and/or raw data) to measure change. In general, each SBCC finding (which was developed after extensive desk review of documents, including the baseline reports of the aforementioned assessments/evaluations) will be compared to the data sources listed in Table 7. Where evidence is not sufficient or clear at the report level, findings may be further compared and analyzed next to the raw data.

SBCC Objective	What are we planning to measure?	Data Source
Objective 1.1: Reduce stigmatizing attitudes and behavior towards persons with disabilities within families and the wider community.	Changes in prevalence of families and the community's stigmatizing attitudes and behaviors towards persons with disabilities.	Compare SBCC finding #4 to: - The CBID Demonstration Model Assessment Endline report - Raw data from USAID Okard Endline Quantitative Survey-long form. Section G: (Knowledge & Attitude to Inclusive Development). - Raw data from qualitative data collection (FGD and In-Depth Interview (IDI) with stakeholders. - Section C (Awareness & attitudes to disability) and G (Questions on discrimination). - Relevant qualitative data from the SBCC interventions implemented by sub-recipients *Raw Data will be analyzed as required.*
Objective 1.2: Raise awareness of the skills, ability, and potential of persons with disabilities to work and contribute positively to their community.	Changes in community member's attitudes about skills, ability, and potential of persons with disabilities (in terms of work and/ or community participation)	Compare SBCC finding #5 and #8 to: – CBID Demonstration Model Assessment Endline report. – Raw data from USAID Okard CBID Endline Quantitative Survey tool- long form: Section F (Access to the Community), G. (Knowledge & Attitude to Inclusive Development). – Raw data from USAID Okard CBID Endline Qualitative data collection (FGD and IDI with stakeholders) in Section B (Inclusion and Participation in the community), Section C

		(Awareness & attitudes to disability), and Section D (Work and Social Participation).
		– Relevant qualitative data from the SBCC interventions implemented by sub-recipients
		Raw Data will be analyzed as required.
	Changes in attitudes and practices of employers towards employing persons with disabilities.	Compare SBCC finding #5 and #8 to:
		– USAID Okard Performance Evaluation Midline and Endline report relates to IDI with employers and private sectors representatives.
		– CBID Demonstration Model Assessment Endline report.
		– Raw data from USAID Okard CBID qualitative data (FGD and IDI with stakeholders) in Section D (Work & Social Participation).
		– Relevant qualitative data from the SBCC interventions implemented by sub-recipients
		Raw Data will be analyzed as required.

Objective 1.3: Sensitize family members to recognize and support the potential of persons with disabilities.	Changes in family members' attitudes about the potential of persons with disabilities. Changes in family members' behavior towards supporting the potential of persons with disabilities.	Compare SBCC finding #5 and #6 to: – CBID Demonstration Model Assessment–Endline report. – Raw data from USAID Okard CBID Endline Quantitative Survey tool- long form: Section G (knowledge & Attitude to Inclusive Development) – Raw data from USAID Okard CBID Qualitative data (FGD and IDI) in Section B (Inclusion and Participation in the community). – Relevant qualitative data from the SBCC interventions implemented by sub-recipients *Raw Data will be analyzed if required*
Objective 1.4: Increase confidence of persons with disabilities to engage more actively in society.	Change of persons with disabilities' participation (attendance) in social events e.g., village meetings, festivals.	Compare SBCC finding #4 and #5 to: – CBID Demonstration Model Assessment–Endline report. – Initial and discharge interview results from CBID Case Management Modular Tool Raw Data Module 2 (questions related to participation).

	Change of persons with disabilities' participation (active contribution) in social events e.g., village meetings, festivals.	– Raw data from USAID Okard CBID Endline Quantitative Survey tool- long form: Section F (Access to the community). – Raw data from Qualitative data (FGD and IDI) in Section B (Inclusion and Participation in the community) & D (Work & Social Participation). – Relevant qualitative data from the SBCC interventions implemented by sub-recipients *Raw Data will be analyzed if required*
Objective 2.1: Increase knowledge of health service providers, including traditional sources, at all levels of the health system about the definition and scope of rehabilitation and its benefits.	Change in health service providers (including traditional sources) ability to: - Accurately define rehabilitation - State the scope of rehabilitation services - State, and belief in, the benefits of rehabilitation	Compare SBCC finding #3 to: – USAID Okard Performance Evaluation Midline and Endline report. – CBID Demonstration Model Assessment–Endline related to IDI with health professionals on the section of Knowledge, Attitude and Practice. – Baseline and Endline result of Rehabilitation survey. – Knowledge assessment result (Pre-Post test) on rehabilitation for the traditional sources in the health discussion group. ** Rehabilitation survey and health discussion groups are specific activities under the Department of Healthcare and Rehabilitation scope of work/ proposal and budget (DHR 6.1 & DHR. 6.3)*

Objective 2.2: Increase knowledge of community members on health conditions and related difficulties in functioning, and the available medical and rehabilitation services available through providing clear and evidence-based information materials and sources.	Change in community members ability to: - State / differentiate a variety of health conditions - State related difficulties in functioning - State available medical and rehabilitation services (in relation to health conditions and difficulties in functioning).	Compare SBCC finding #1 and #2 to: – CBID Demonstration Model Assessment Endline report. – Initial and discharge interview results from CBID Case Management Modular Tool Raw Data Module 6 (questions related to access to and utilization of health services. – Raw data from USAID Okard CBID Endline Quantitative Survey tool- long form: Section D (Health and Access to Health Service). – Raw data from qualitative data (FGD and IDI) in Section E (Access to Service).
	Change in health seeking behavior of community members (when comparing initial and discharge interview results). - Frequency of behavior (accessing available medical and rehabilitation services) - Choice of provider/ service	
	Change in number of community members accessing rehabilitation services.	

Table 7: Data sources mapped to each SBCC objective to demonstrate how change will be measured for each objective.

9.2. Output Measurement (Interventions)

Results of the SBCC interventions (outputs) implemented by USAID Okard sub-recipients will be measured using quantitative indicators. Each sub-recipient is contributing to and reporting to the SBCC Coordinator on one or more of the output indicators, depending on the type of SBCC intervention they are implementing (see Table 8 below). The sub-recipients will report the output progress after the implementation of each activity, as well as provide a summary in their quarterly report (to either WEI or HI). WEI will report the output progress to USAID on the quarterly basis. One of the output indicators (SBCC-1) aligns with the USAID Okard results framework and will contribute data reported to USAID through USAID Okard indicator PM-1.[75]

In addition to the quantitative data (output), qualitative data from the interventions (for example, questions harvested from discussion groups, or non-verbal and verbal reactions to storytelling videos, and online discussions), relevant to the objectives and measurement of change (outcomes) in Table 7 will be tracked by the SBCC Coordinator quarterly. To support this qualitative analysis, the sub-recipients will submit qualitative data such as questions or transcripts or screenshots of social media engagement to the SBCC Coordinator, who will screen the data and identify relevant data. The relevant themes and changes identified will be used as a data source for outcome measurement, and reported on in the SBCC Evaluation Report.

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[75] Indicator PM-1 measures the number of beneficiaries who have received training and/or attended an awareness raising activity and demonstrated increased knowledge, skills, and awareness as a result of the United States Government assistance.

Indicator Name and code	Description/ Definition	Data collection Method	Data Source
SBCC-1: Number of target audience members reached by SBCC intervention	Target audience members include persons with disabilities and their family members, local authorities, religious representatives, and villagers who joined SBCC interventions. 'Reached' = Increased awareness through increased recognition of rights, services (including mechanisms for obtaining services), laws, and policies (gained from attending awareness raising activities or training opportunities). 'SBCC interventions': Discussion group, storytelling, storytelling competition, online discussion, honoring change, and launch of awareness raising materials on rehabilitation. Note: This indicator contributes to the USAID Okard indicator PM-1 in the USAID Okard result framework.	Registration/ attendance sheet (paper or online) Reported number of people reached from social media platform	QLA ARMI DMAS DHR & CMR HI
SBCC-2: Number of questions harvested during discussion	Questions or feedback/comments shared / asked by a participant during a discussion group (face to face or online) that are relevant to/ demonstrate a person's knowledge, attitude or practice related to disabilities / disability inclusion.	Facilitator notes or transcript from discussion group. Screenshot of social media online discussion.	QLA ARMI DMAS DHR & CMR HI

| SBCC-3:

Number of audience members who interacted with media medium by calling in, sending suggestions, comments, and/or sharing stories | Audience members refers to persons with disabilities and their family members, local authorities, religious representatives, and villagers who joined SBCC interventions.

Examples of media medium include:

1. Videos/stories that have content related to changes in attitude and behavior, showcasing success stories, role models, interviews with experts, persons with disabilities, presenting predicaments for discussion, challenges and solutions, instructional videos, training videos.

2. Questions posted on social media that are relevant to/ demonstrate a person's knowledge, attitude or practice related to disabilities / disability inclusion.

3. Other media medium such as leaflet, poster, and/or social media post that invite responses, comments or stories from the audiences with relevant to/ demonstrate a person's knowledge, attitude or practice related to disabilities / disability inclusion.

The sharing platform could include:

- Focus Group Discussion
- Social Media
- SBCC community event | Responses in social media platform and text message

Facilitator notes or transcript from Group Discussion | ARMI

DMAS

HI

DHR & CMR |

SBCC-4: Number of times people or communities are publicly recognized by NCDE for their change or commitment to change to be more disability inclusive	'Publicly recognized' = verbal or written recognition by a staff member of NCDE to an audience of people outside of NCDE (general public, other GOL officials). Examples of 'verbal or written means' = a speech, social media post, report, quote in a newspaper article, remarks at an event etc.	Report, meeting minutes, transcripts or video clips of speeches, or screenshots of official social media, newspaper articles from the events, activities.	NCDE

Table 8 : SBCC Interventions - Quantitative indicators reference guide

X. References

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Annex

Annex A. Reaching for a Better life Workshop Report

Workshop Report
Reaching for a Better Life Workshop

Date: 29-30 January, 2020
Location: The International Cooperation Training Center (ICTC) in Vientiane Capital
Conducted by: Sathaphon Phoumarinno (SBCC Coordinator), C.Y. Gopinath (SBCC Consultant)
Report written by: Sathaphon Phoumarinno

1. Background

Social and Behavior Change Communication (SBCC) is a cross-cutting activity of the USAID Okard project across the health, economic empowerment, and stakeholder engagement, and Community Based Inclusive Development (CBID) components. The two-day community consultation, "Reaching for a Better Life," was an information gathering workshop for the SBCC Strategy and Action Plan. The workshop aimed to fill information gaps following the desk research and validate research findings with stakeholders and community members. It was an experiential process that used methods such as role plays and discussions to explore dilemmas and issues around health, caregiving, employment and community engagement among persons with disabilities, their families, and their communities. The workshop explored issues such as stigma, knowledge gaps, information sources, health priorities and preferences in communication channels.

2. Workshop Objectives and Participants

The objectives of this community consultation workshop were:
1. To gain additional specialized insights and inputs from disabled persons, their families and their networks in order to refine and finalize the SBCC strategic approach. These areas include —
    i. Dilemmas and perceptions around stigma, health-seeking, self-perception, predicaments and aspirations among disabled persons and those linked to them through family ties, health and other relationships.
    ii. How health-related decisions and socio-economic choices are made within families, and the priority given to health and education, especially regarding disabled persons.
    iii. Information gaps and needs of disabled persons, their families, as well as healthcare professionals and employers regarding disabilities, competencies, and care needs.

iv. To identify and assess trusted information sources, preferred media, social media use and other priority communication channels.

2. To validate the insights and findings of the desk research and literature review with community members, persons with disabilities and other stakeholders.

The workshop was attended by 60 participants, including 41 men and 19 women. The following groups were represented —

- Central Government: Ministry of Labour and Social Welfare, Ministry of Health, Centre of Medical Rehabilitation, Center of Communication and Education Health, Mahosot hospital.
- Provincial Government: Provincial Labor and Social Welfare Department; Provincial Health Department; District Labor and Social Welfare Office, District Health Office, Provincial Rehabilitation Center.
- International Non-Governmental Organization (INGOs): World Education Laos, Humanity and Inclusion.
- Disabled People's Organization (DPO) and Non-Profit Association (NPA): Lao Disabled People's Association, Quality of Life Association, Association for Rural Mobilisation and Improvement,
- Social Enterprise: Disability Mainstreaming Adversary Service (DMAS) Center
- Community: Village authorities, teacher, doctor and nurse, persons who is deaf, persons who is blind, persons with limb amputation, caregiver (family members), employer, monk, traditional healer (herbalist) and pharmacist.

3. Workshop Design and Methodology

1. Participation was anonymized: Participants were asked to use made-up names during the workshop. This reduced the influence of known status and hierarchies.
2. Role Play was used: This allowed participants to step outside their own personality and viewpoints by role-playing other persons.
3. Predicaments and dilemmas were used: While remaining in roles, participants were asked to resolve problems and dilemmas around health, well-being, choices, priorities and disabilities.
4. The facilitators asked questions to deepen dialogue among participants.
5. A team of five non-participant observers took notes.

4. Contents of the Workshop

The workshop consisted of a series of small group activities such as designing a fictional family budget or discussing which persons with disabilities could be employed at a certain type of business, large group role-play activities, such as pretending to be a community advising a woman with mobility impairment on whether or not to have a baby, and answering questions

related to rehabilitation, disability, and social inclusion. At the end of the workshop, facilitators presented the SBCC research and workshop findings, and participants discussed and voted on whether they agreed with these findings. For the full agenda, please see Annex 2.

5. Workshop Outcomes

Key Insights from Information Gathering Activities:

- Major barriers for persons with disability identified are difficulty getting hired, negative attitudes from society, and difficulty accessing services because of physical accessibility, difficulty communicating, and cost.
- There was some uncertainty about the causes of disability and whether it could be caused by sins from a past life or not.
- Caregiving can feel like a burdensome obligation and can be overwhelming for families.
- People feel that in theory, there are many jobs that a person with disability can do, but in practice, employers do not want to dedicate extra time or investment into additional training or physical accessibility adjustments for them.
- Official notice letter to the village chief, who can then share with village members, is an important means of communication. For reaching younger students, teachers can help; for reaching older students, Facebook and posters are especially effective; and for adults, TV, word of mouth, and newspapers are also helpful. Creative ways of sharing information could be puppetry, soap opera, movies, or storytelling.

Cross-validation of Findings:

- Three new items were added to the list of SBCC findings based on the workshop results:
  - The family plays a key role in positive and negative outcomes.
  - Education can be deprioritized in adverse circumstances.
  - There is hesitation in disclosing or discussing traditional beliefs in public.
- Participants voted on the SBCC findings with the following results:

Findings	Question	YES	NO
1	Clear accurate medical knowledge of disabilities is limited in the community	38	2
2	People turn to local sources for understanding.	19	19
3	Poor general understanding of rehabilitation, even among health care staff. [Note: There was some confusion about the translation of this finding.]	30	8
4	Caregiving sometimes places a disproportionate burden on some family members.	38	0

5	Fear and poor understanding of disability leads to social exclusion, stigma, teasing.	34	7
6	Lack of focus on abilities [the dominant focus is on disabilities]	38	1
7	The family plays a key role in positive and negative outcomes.	38	0
8	Education can be deprioritized in adverse circumstances.	29	8
9	There is hesitation in disclosing or discussing traditional beliefs in public.	19	17

6. Workshop Evaluation (Feedback from trainees)

After finishing the workshop, participants filled in a workshop assessment form. Please see results and comments of interest below.

A. Things people liked about the workshop
- Most of participants agree that this kind of workshop is very new with participatory and interactive approaches. About 25 participants said that they liked the discussion and brainstorming in the groups, and other particularly like the role play and problem-solving activities.
- More than 10 participants impressed with the inclusive envelopment where everyone regardless of sexes, disabilities and ethnicities can actively participate and feel free to express their thoughts.
- Participants were pleased with the workshop location and thoughtful preparation by organizers and facilitators.

B. Things which could be improved about the workshop
- Some Lao language instructions/materials were not clear or too technical for some participants. Some participants suggested having materials in braille also.
- Participants who could not read or write had difficulty with some activities, and next time there should be someone to sit with them and assist them.
- Some participants suggested to have a session learning about disabilities by inviting a technical expert, and they can provide more information on types of impairments, their causes, and how to take care of them.

C. Things people learnt about SBCC from the workshop
- Learning about disability and inclusion is one of the valuable take away lessons for participants. They did not only get to hear about the rights and need of persons with disabilities, but also the barriers and challenges that hinder their full participation in community.
- Participants became aware of the importance of communication and channel to communicate with audiences as well as what type of messages should be used based on the communication tools.

- Participants learned about different methodologies to consider the issues related attitude and behavior towards persons with disabilities.

The Community Consultation Workshop in Vientiane 29-30 January 2020

Annex B. Figureheads Tool

Figureheads role-play is a participatory exercise that enables an exploration of complex personal issues related to disability and inclusion. Figureheads works like a slow 'massage' that first moves the group towards introspection and comment about various experiences, and finally brings about a full sharing of personal experiences and observations. The game helps unravel knowledge, attitudes, beliefs, and practices as they exist in their pristine state.

The main objectives of Figureheads are:

1. To understand how to set up and conduct a session of Figureheads.

2. To understand the importance of experience sharing as an outcome of Figureheads.

The Figureheads role play will take approximately 75 minutes.

What is a **Dilemma?**

A dilemma is a special kind of problem in which a person cannot choose between different options, because each option leads to some new problem

Example: A young truck driver loves his wife and child and has a happy family life. On a trip, he becomes infected with HIV after having unprotected sex with a stranger. He finds out when he goes for a test. If he tells his wife that he is HIV positive, he fears she will leave him. If he pretends nothing is wrong and has sex with her, he is afraid he will infect her as well. If he refuses to have sex, she will wonder why. And if he begins using condoms, she would become suspicious.

The truck driver has a dilemma. No matter which option he chooses, it leads to a new problem.

Figureheads process:

Before the session:

Select a participant to play the part of the Dilemma Holder in the session, and share the dilemma sheet with him or her. When called upon, the Dilemma Holder should share his or her story with the group, using their own words, without adding extra details. They should give themselves a name.

Seat participants as shown in the diagram below, with chairs to seat the panel of 6 or 7 figureheads.

THE COMMUNITY (Other participants)

Dilemma Holder
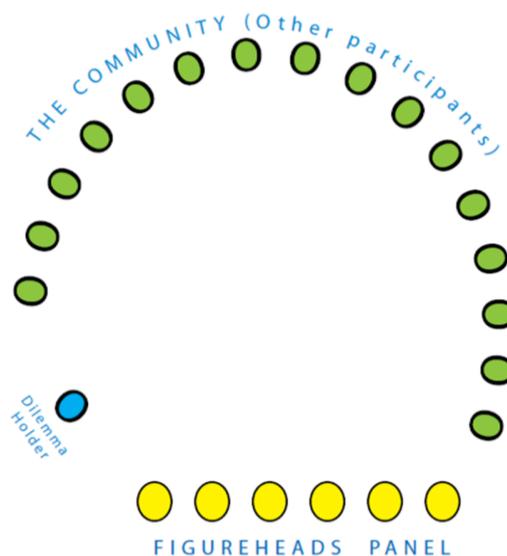
FIGUREHEADS PANEL

Introduction (5-10 minutes)

To be conducted only the first time you conduct Figureheads with a group.

1. Discuss with participants what they understand by the word 'Figurehead'. Explain that in this session, a Figurehead refers to a member of the community or family who plays a responsible and well understood role in the community. Examples: Teacher, judge, chief, monk, doctor, parent, and police.

2. Ask participants to suggest some Figureheads for this session. Select 6 or 7, and write each figurehead's name on an A4 sized placard.

3. Ask for volunteers to role play each Figurehead. Ask the volunteers to sit in chairs in front of the group, holding their placards up.

Round 1 (15-20 minutes)

1. Call the Dilemma Holder before the group and ask him or her to share the dilemma with the panel of Figureheads.

2. Ask the Dilemma Holder to select a Figurehead from whom he or she would like a solution for the dilemma. Let the selected figurehead offer advice to the Dilemma Holder.

3. Now ask any other Figurehead to improve upon all the advice they have heard so far.

4. Repeat Step 3 until all the Figureheads have given advice to the Dilemma Holder.

Round 2 (25-45 minutes)

5. Summarize the different suggestion made by the Figureheads.

6. Ask the Dilemma Holder if he or she felt that their problem was addressed, and if they now have different useful or interesting options to think about.

7. Whatever the Dilemma Holder feels, now ask the remaining participants if they can now improve on the suggestions that have come from the Figureheads. Ask questions, challenge, and provoke, as other participants offer advice.

Round 3 (20-30 minutes)

8. Invite all the players. Including those who played Figurehead roles, to share their own real-life experiences and reactions to that particular dilemma. Typical guiding questions are:

- Has anyone you know had an experience like this?

- How was the experience different from the dilemma we just examined?

- How did you/they react to it?

- How did you/they solve it?

- Is it a common dilemma?

- Who is the best person to approach for help?

- Why does this dilemma occur in a person's life?

9. End the session when about 6 to 8 individuals have shared experiences.

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Notes to Facilitators

1. Why does Figureheads work?

Figurehead works because it creates a 'safe space' by asking participants to discuss an 'imaginary' dilemma through role play. No one feels targeted during the game. Participants move gently from role-play to real life experiences.

2. What purpose do the Figureheads serve?

The purpose of asking volunteers to role-play community figureheads is to increase the chances of diversity in advice. By asking Figureheads to improve on each other's advice to the Dilemma, the facilitator ensures that a range of solutions as proposed for discussion.

3. Why is it important to have diversity in opinions expressed?

The more differing advice is given by the Figureheads in Round 1, the greater number of options that participants will react to in Round2. This improves the quality of Experience Sharing in Round3.

4. What is the objective of the Figureheads Game?

The goal of the game is to bring about a sharing of real-life experiences, problems, and practical, real-life solutions. This happens in Round 3.

Important: The objective of the game is not to find out what community figureheads think about an issue, or to help participants decide who to turn to when in trouble. Figureheads is also not a problem-solving game but an experience-sharing game. Individuals should be encouraged to arrive at their own choices. A dilemma does not have a right or wrong answer. Each individual must arrive at an independent decision on what will work best for them.

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Annex C. Timeline Session Tools

How to conduct a Timeline session

A Timeline session gives the facilitator a structured method for exploring specific issues using role play in a safe space where participants can explore and express their own understanding, knowledge, attitudes, and feelings. Examples of relevant issues are bullying, social exclusion, holding negative views about persons with disabilities, belittling their worth, excluding them from employment, and preferring shamanistic rituals over clinical rehabilitation.

The 11 stages of a Timeline Session

1. Generate a story

2. Enact a role play and freeze

3. Explore thoughts and feelings

4. Define the Crisis

5. Explore the Childhood

6. Explore the Adolescence

7. Discuss Causes

8. Explore Future Timeline

9. Discuss Consequences

10. Share real life experiences

Each of these will be detailed below.

Components of a Timeline Session

The Crisis

The incident that contains the issue or problem is called the **crisis.** There may be one person or two in a crisis.

A crisis may be something that has already happened, or something that is about to happen.

A crisis evokes strong emotional reactions, and can bring about strong attitudes and beliefs. For example, a woman with disabilities who has been bullied may not go out or socialize, and may believe that persons with disabilities should only stay home.

A crisis leads people to make behavior choices that can change their lives permanently for the better or the worse. Timeline helps us to explore these options.

The Key Player

The Key Player will generally be the one whose behavior needs to shift. Depending on the group and the intervention, the Key Player could be the one in a difficult situation such as being bullied, being discriminated against, socially excluded, or facing difficulties in accessing health facilities or employment. In other cases, the Key Player might also be the person who, through their actions, creates a traumatic or destructive crisis.

Conducting a Timeline Session

Prepare the setting. Rearrange participants on two sides of the room to clear a corridor between them almost equal to the length of the room. This is called the Timeline Corridor. One end of the Timeline Corridor represents the Key Player's past (childhood and adolescence). The other end represents the Key Player's future, including his or her death. Somewhere between these two is the **Present Moment,** in which the Crisis has occurred.

1. Generate a story. The facilitator must know the topic they wish to explore, e.g., social exclusion. The facilitator will use an everyday object such as a pen or a glass to trigger the participants' imagination and rapidly ask questions to extract details of a story related to that topic. The facilitator will start the session with a simple statement such as, "This pen belongs to a young man with a mental health problem who was locked in a room all day."

By asking specific, detailed questions, the facilitator will now extract details from the participants, using their imagination. They must set up a brisk tempo, not leaving much time for overthinking. Some examples of questions:

- o What is the name of the person with the mental illness? Location?
- o What is his/her age?
- o Which parent locked him up?
- o Why was he locked up?
- o How tall is he?
- o What time of day was it?
- o How tall is the person?
- o Which parent spoke up against locking him up?

o   Were the parents going somewhere? What was the event?

  o   How did the parents settle the argument?

The facilitator may need 30 to 40 questions to get enough detail to make the story come alive in detail. To help participants visualize the emerging story, the facilitator should summarize the growing details every few minutes.

2. Enact a role play and freeze. In this step, the story and characters created by the community of participants will be brought to life in a role play. Invite three participants to step up and enact the story of the argument between two parents who were headed for a social event, and who decide to lock up their son "for his own good."

Ask participants to rate the quality of the role play in terms of entertainment and authenticity, then invite different participants to enact the same role play and improve upon it. After two or three sets, ask participants to choose the best of them, and ask them to re-enact it. Tell them that when you call out, "Freeze!", they must freeze in mid-action.

Call out "Freeze!" just before the moment of Crisis, in this case the moment when the young man is locked up.

3. Explore thoughts and feelings: Tell participants that the freeze represents the moment before something terrible happens. Ask them to speak out and say what they think is going on in the minds of each of the role players. For example, ask, "What is the young man with the mental problem thinking?"

Ask participants to reply in the first person, as though they were the young man.

In this manner, explore the feelings and thoughts of each participant, allowing them to add to each other's answers.

4. Define the Crisis. Ask participants whose behavior needs to change. Tell them that this person will be called the Key Player. In this case, the crisis has been caused by the behavior of the father, who is therefore the Key Player in this story. The boy with mental illness is the target. **Example:** *The father aggressively insists that his son with a mental illness should be locked, against the mother's wishes. This creates a trauma and crisis in the life of the young boy.* Use questions like these to help participants in the Crisis.

  o   What has the Key Player done? Or what was done to this person?

  o   How does the Target feel about what happened?

  o   How does the Key Player feel about what he is going to do?

  o   Is this the first time such an incident has occurred?

  o   What sort of life lies ahead for the Target?

5. Explore the Childhood. Place a chair in the Time Corridor, in a spot roughly matching the Key Player's age. Explain to participants that this position represents the present moment; the Key Player's age today. Seat the Key Player in the chair.

Explain that we want to find out the kind of experiences and influences the Key Player went through which made him think that locking up his son was the best thing to do. Move the chair back a few feet towards the past and explain that this is the Key Player as a child, at around age 10. Explore the Key Player's quality of life and experiences at that time. The following are some sample questions:

o What was the quality of the relationship between the Key Player's parents? Neighbor?

o As a child, did the Key Player see any persons with disabilities?

o Was the Key Player loved as a child?

o What sort of child was the Key Player (e.g., Quiet, sociable, difficult, introverted)?

o How many brothers and sisters were there in the family? What was the relationship between them?

o Which was the most disturbing event the Key Player observed as a child?

o What were the Key Player's difficulties during childhood?

o What attitude did the Key Player observe towards disabilities?

o Did the Key Player have friends in school or near home? What were the good friendship experiences? What were the bad friendship experiences?

o What good behavior did the Key Player learn from childhood? What bad behavior did the Key Player learn?

6. Explore the Adolescence. Move the chair slightly into the future, roughly towards the teenage years, and explain that this represents the Key Player at the end of his/her teenage years, at around age 18. Explore the experiences and influences of the Key Player's adolescence, especially as they relate to disabilities, inabilities, and poor performance. Did the Key Player ever experience public humiliation or shaming because of the lack of a skill? The following are some sample questions:

o At age 18, has the Key Player been bullied?

o When and how did it happen? What was the experience like for the Key Player?

o Does the Key Player try to stand up for themselves?

7. Discuss causes. Ask participants how the Key Player's past experiences and attitudes seem to have led to the current crisis. The following are some sample questions:

- o What attitudes did the Key Player form about disabilities, bullying, and social inclusion, as a result of childhood and adolescent experiences?
- o How have the Key Player's attitudes led to his or her current behavior?

8. Explore the Future: Move the chair well beyond the Present Moment, and explain that this is the Key Player in late life, about 10 to 15 years beyond the present. Explore what life is like now for the Key Player. The following are some sample questions:

- o What is the Key Player's life like now?
- o What is his behavior like?
- o What is the Target's life like now?
- o What kind of behavior does he/she practice?
- o What kind of relationship does the Key Player have with his/her family, neighbor?
- o How is the Key Player's current family life the result of past behavior decisions?
- o What is the best possible life situation for the Key Player today?
- o What behavior option should he/she have chosen in the past to enjoy the best possible life today?

9. Discuss Consequences. Discuss how past behavior choices, experiences, and attitudes could have led the Key Player to a crisis in social exclusion. Discuss how the Crisis itself could lead the Key Player to new behavior. Analyze the Key Player's behavior options after the crisis. Which behavior choice could lead to the happiest possible future for the Key Player?

10. Share real life consequences: Ask participants if they know similar stories from real life, and if they could share them, without revealing anyone's identity or location.