





Operational Guidance for the Rights to Participation of Adolescents and Youth with Disabilities in Timor-Leste





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1. INTRODUCTION

1.1 Background and rationale for this guidance document

The rights of children and adolescents are protected by the Convention on the Rights of the Child (CRC), which Timor-Leste has ratified. One of the rights of children is the right to participation. This means that children have the right to freely express their views on all matters and decisions that affect them, and to have those views considered at all levels of society. This is well-recognized in Timor-Leste's National Youth Policy, which includes a goal area on civic participation.

Participation is critical, since children, adolescents and youth are directly affected by the decisions that the country's leaders make, particularly in the education, health, and employment sectors, yet adolescents and youth are often excluded from decision-making. Adolescents and youth have innovative and creative views on matters that shape their lives and communities. They have the right to be heard, the right to engage with governments and decision-makers, and the right to influence matters that affect them. This applies to all adolescents and youth – regardless of their background, of their gender, or whether they have a disability or not. Despite efforts by the government and other decision-makers to facilitate their civic participation, adolescents and youth with disabilities continue to experience significant barriers to full and meaningful engagement.

This operational guidance for the rights to participation of adolescents and youth with disabilities has been developed by UNICEF Timor-Leste in partnership with the Secretary of State for Youth and Sports (SSYS) Timor-Leste to provide useful guidance for all government entities, development partners, non-governmental organizations (NGOs) and civil society organizations (CSOs) to engage adolescents and youth with disabilities in activities and events.

1.2 Key concepts

1.2.1 Civic participation

Civic participation is the human right for every member of the society to express their views and influence matters that affect them directly and indirectly at different levels of society: individual, families, communities, and states. Adolescents and youth not only have a right to be heard, they are a crucial resource of innovative ideas for communities. Civically engaged adolescents and youth are empowered to drive change. Giving adolescents a chance to speak is not sufficient to ensure meaningful participation; it also requires a safe space, informed views, an audience, and influence.

1.2.2 Disability

Disability is a complex and evolving concept, involving aspects of body function and structure (impairments), capacity (measured by the ability to carry out basic activities without the benefit of assistance in any form) and performance (measured by the individual's ability to carry out these same basic activities using available assistive technologies and support). In Timor-Leste, disabilities are often categorized into four areas: physical, hearing, seeing, and mental.

As stated in the Convention on the Rights of Persons with Disabilities (CRPD), disability stems from the interaction between certain conditions or impairments and an unaccommodating environment that hinders an individual's full and effective participation in society on an equal basis with others. [UNICEF 2022]

The framework of the International Classification of Functioning, Disability and Health (ICF) relies on a three-level model to describe the concept of disability. According to the ICF, disability can occur as:

- An impairment in body function or structure (for example, a cataract or opacity of the natural lens of the eye, which prevents the passage of rays of light and impairs or destroys sight)
- A limitation in activity (for example, low vision or inability to see, read or engage in other activities)

 A restriction in participation (for example, exclusion from school or participation in other social, recreational, or other events or roles). [WHO]

The phrase, "person with disability," assumes that all disabilities are alike but this group is varied and has a range of needs. Two people with the same type of disability can have vastly different needs. Some types of disabilities could be concealed or hard to identify.

Impairments

The extent to which an impairment limits a person's daily functioning will be different for everyone. For some people their impairments may be at a level that makes daily activities a little difficult, but for others their impairment may be at a level that makes daily activities very difficult.

Types of Impairments

- **Physical** difficulty in the performance of body functions (e.g. walking, moving arms and legs, using hands, etc)
- **Sensory** difficulty seeing, hearing, or communicating (e.g. people who are deaf, hard of hearing, blind or have low vision)
- **Mental** difficulty maintaining concentration, attention, memory and energy; difficulty with mood changes and perceptions; psychosocial distress
- Cognitive difficulty with language, reasoning, memory, learning.

1.3 Defining rights of adolescents and youth with disabilities

The rights of adolescents (ages 10 to 19 years) and youth (ages 15 to 24 years) with disabilities are protected under international law.

List of rights

The rights of children are protected by the Convention on the Rights of the Child (CRC), which Timor-Leste has ratified. The right to participation is enshrined in article 12 of the CRC. Adolescents and youth have the right to unrestricted participation in all activities that directly

and indirectly impact them. For this, as the primary duty bearer, the State has a responsibility to foster an environment for adolescents and youth to enjoy their rights to participation.

Timor-Leste has not yet ratified the Convention on the Rights of Persons with Disabilities (CRPD), which is to promote and protect the rights of people with disabilities. At the state level, people with disabilities are entitled to the same rights as all Timorese citizens under the Constitution of Timor-Leste.

Below is non-exhaustive list of rights of adolescents and youth with disabilities:

- Right to be healthy
- Right to education
- Right to be safe
- Right to be heard
- Right to be informed

1.4 Key barriers to civic participation of adolescents and youth with disabilities in Timor-Leste

Barriers are factors in a person's environment that, through their absence or presence, limit functioning and create disability.

Types of Barriers

- Physical barriers: uneven ground, narrow doorways, inaccessible latrines and water
 points, inaccessible transport etc. Almost all buildings in Timor-Leste (public or private)
 lack accessibility features such as ramps, guiding blocks, and accessible toilets. Assistive
 technology (assistive, adaptive, and rehabilitative devices), such as hearing aids, braille
 embossers, crutches, wheelchairs, are not available to all people with disabilities
- Social barriers: negative attitudes and beliefs about impairments can be demonstrated by stigma, discrimination, negative assumptions, teasing/name calling. Attitudinal barriers can become negative social norms. Negative attitudes towards people with disabilities and use of discriminatory language are often observed/heard in communities

- Communication barriers: lack of sign language interpreters, braille or large print etc
- Institutional barriers: discriminatory laws, policies, or practices, including no budget or funding to support reasonable accommodations, not accounting for the specific needs and interests of people with disabilities. Public services, systems and policies are not disability friendly. For example, lack of braille textbooks, and no national disability sign language.

1.5 How this guidance was developed

This guideline was developed based on existing literature and consultations with 74 stakeholders consisting of adolescents and youth with disabilities, their parents, community leaders and members, youth representatives, youth centres, and organizations of people with disabilities (OPDs) from the municipalities of Dili, Ermera, and Bobonaro.

	Dili	i	Bobonaro Ermera		Total				
	Female	Male	Female	Male	Female	Male	Female	Male	Total
OPDs	3	1	2	2	2	2	7	5	12
People with disabilities	1	3	2	2	2	2	5	7	12
Parents/caregivers of									
people with									
disabilities	2	2	4	0	3	1	9	3	12
Community leaders	0	4	2	2	0	4	2	10	12
Community members	0	4	3	3	1	3	4	10	14
Youth centre staff	2	2	2	2	1	3	5	7	12
Total					32	42	74		

A workshop was held with relevant government institutions and OPDs to validate the information. The draft operational guidance was also reviewed by CBM Australia.

2. PRACTICAL GUIDANCE FOR CIVIC PARTICIPATION OF ADOLESCENTS AND YOUTH WITH DISABILITIES

This section presents practical guidance for civic participation. The guidance can be used for three types of activities: content development, training, and consultation for and with adolescents and youth with disabilities. The following guidelines will support you to plan your activities and include adolescents and youth with disabilities in meaningful civic participation.

2.1 Identify adolescents and youth with disabilities to participate in activity

You must first know how and where to contact adolescents and youth with disabilities. Below are some ways to find them.

Reach out to organizations for people with disabilities (OPDs)

- OPDs have beneficiary and member lists. The lists include information on name, gender, age, address, type of disability and even pictures/photographs in some cases. (See annex 1 for a list of OPDs and contact information for each municipality)
- The lists may include only those individuals that fit their programmatic requirements (e.g. people with vision impairments only). Lists may not be regularly updated.

Reach out to subnational authorities

• The Ministry of Social Solidarity and Inclusion (MSSI) collects information on name, age, type of disability, address, and contact number. Suco (village) chiefs keep this information.

Reach out directly to adolescents and youth with disabilities

• Adolescents and youth with disabilities are often hang out with their peers in OPD offices.

Note: discuss with OPDs to what extent they can share beneficiaries' information. Do not ask for information that you do not need and consider privacy and confidentiality.

2.2 Work with parents of adolescents and youth with disabilities to support their child's participation

After identifying adolescents and youth with disabilities you would like to engage in your activity, it's important to first build trust with their parents and address any concerns they have about their children's participation in your activity.

Build trust and a positive relationship with parents and communities

Hold a workshop with parents and communities to explain in detail who you are, your
objectives, how you will deliver the activities, and how you will take care of adolescents
and youth with disabilities. Being transparent and honest is important to build trust.

Ensure meaningful participation

• You might need to overcome some parents' beliefs that people with disabilities should stay at home. Conduct counselling and awareness raising sessions with parents around their children's capacity to participate, the value of participation for their children, and benefits that adolescents and youth with disabilities can derive from participating in your activity (e.g. activities build skills that can lead to potential employment opportunities). Parents will be supportive once they understand how your activity benefits their children.

2.3 Involve OPDs in the activity

Involving OPDs from the beginning helps you to organize your activity in an inclusive manner.

OPDs are experienced at engaging with adolescents and youth with disabilities.

- Practical help and special support: OPDs can support with transport arrangements and
 act as care providers during activities. They can also procure special assistive devices (e.g.
 wheelchair, cane) and help to communicate or explain details during your activity
- **Encouragement:** adolescents and youth with disabilities feel more comfortable, empowered, and confident when OPDs are with them
- Familiarity: OPDs understand adolescents and youth with disabilities' needs, capacities, strengths and weaknesses

• **Trust:** OPDs have a positive relationship with parents/caregivers who are also at ease when their children are with OPDs.

2.4 Choose a location to accommodate the needs of adolescent and youth with disabilities

Adolescents and youth with disabilities have different needs in terms of venue accessibility. Ideally, the venue should have ramps, accessible toilets, handrails, and guiding blocks.

- **OPD buildings:** some have ramps. Adolescents and youth with disabilities especially beneficiaries of OPDs are familiar with the buildings so it is easier for them to navigate
- SSYS building in Dili: has a ramp, handrails, guiding blocks, and accessible toilets
- MSSI buildings in Dili and other municipalities: more accessible than other venues
- Hotels/conference centres: in Dili, conference rooms at Timor Plaza, Hotel Timor, and Novo Tourismo are more accessible than others. In Baucau, Pousada de Baucau has a relatively accessible conference room.

2.5 Prepare early to ensure meaningful participation in the activity

Starting preparations early is essential to help you identify any obstacles and challenges you may encounter before and during your activities.

Preparations for participants and their parents

- Participants and their parents need to thoroughly understand logistical requirements and arrangements, including how to get to the venue, and who provides care (escorting to the venue and during the activity)
- Participants also need to understand the composition of the group, whether activities
 include only adolescents and youth with disabilities, or both with and without disabilities,
 so that they know what to expect.

Preparations for organizers and facilitators

- Organizers and facilitators should have a basic understanding of disability. Start with knowing what types of disabilities participants are living with. Then understand each participant will have different needs and different types of care. This helps you to plan for what logistics and materials they need (e.g. braille for adolescents and youth with vison impairment)
- People still use derogatory terminologies to address people with disabilities. It's very important that organizers and facilitators know what terminologies to use and what derogatory terminologies are inappropriate.

2.6 Languages to use during activities

Most adolescents and youth with disabilities participants in Timor-Leste speak Tetum and/or other local languages. For participants who speak only local languages, you will need an interpreter who can help them understand the contents.

Communicating effectively, particularly with adolescents and youth with different types of impairments, needs special consideration. Please see the following section (2.7) for detail.

2.7 Accessible format preferences for activity content and material

One size does not fill all – each type of disability requires different modes of communication for effective information exchange.

Vision impairment

- Prepare audio recordings instead of printed materials so participants can listen again at home. Recordings can be made with your smartphone (voice recorder app) and shared via WhatsApp
- Prepare materials in braille for those who know how to read braille. Asosiasaun Halibur
 Defisiensia Matan Timor-Leste (AHDMTL) can help you develop braille materials (see
 Annex 1 for contact details). Please note that few people know how to read braille; check
 with participants first

For participants with low vision, use large font and a high contrast colour scheme (e.g. black text on yellow background, white text on black background). Use easily recognizable characters such as Arial, Verdana, Tahoma and Sans Serif fonts. Avoid italics, slanted, all lower-case text, or all upper-case text.

Hearing impairment

- Prepare videos with subtitles in Tetum as well as local languages
- Use sign language for those who know sign language. Please note that few people know how to sign; check with participants first. Take extra time for interpretation into consideration when you make an agenda
- Use very basic sign improvised sign language
- Develop highly visualized written materials using pictures, icons, and illustrations.

Mental/intellectual impairment

• Explanations through games or highly visualized materials using pictures, icons, and illustrations.

General considerations

- Content should first be developed in Tetum and then contextualized and adapted according to audiences' format needs (e.g. video, braille, sign language, local language, add pictures, bigger text)
- Language should be simple, clear, and easy to understand. Avoid jargon and use plenty of examples
- Include pictures, icons, and illustrations to help all participants to absorb the content more easily
- Share materials with participants with disabilities the day before the activity to allow them time for review
- Provide handouts to take home.

2.8 Special assistance for adolescents and youth with disabilities to attend the activity

Once you understand the different needs of your participants, consider what special assistance you can provide.

- Transport: provide safe and accessible transport modes. Consider renting a microlet to transport participants
- Carers: offer practical support to reach the venue, toilets, food, and also during the activities. This is especially necessary if infrastructure is not disability friendly
- Aids: depending on the type of disability, provide wheelchairs, cane/stick, braille, sign
 language interpreter. The National Rehabilitation Centre (CNR), AHDMTL and Klibur
 Defisiensia Tilun Timor-Leste (KDTTL) (see annex 1 for contact details) can assist with
 providing aids. Coordinate with these organizations well in advance.

2.9 Budgetary provisions

Special budgetary provisions are needed to ensure adolescents and youth with disabilities' participation in any activity. The following budget lines should be considered:

- Sign language interpreter: US\$100/month, US\$12/day, US\$1.50/hour (see Annex 1 for contact details of KDTTL). Consider having one sign language interpreter for each group during group work activities
- Wheelchair: US\$1,000 to buy, or request to borrow one from CNR (see Annex 1 for contact details of CNR)
- Walking sticks
- Braille embossers (see Annex 1 for contact detail of AHDMTL and ADTL)
- Transport: U\$\$50-200 per day, depending on the distance, to rent a microlet and driver to pick-up and drop off.

2.10 Activity delivery modalities: hold a separate activity for adolescents and youth with disabilities or one activity that includes everyone

Some adolescents and youth with disabilities may not be comfortable participating in activities with peers without disabilities and vice versa. Depending on the type of activity, it can be challenging to hold one activity for participants with and without disabilities together.

Things to consider

- Adolescents and youth with disabilities' experience: before deciding whether to include
 everyone or hold a separate activity for adolescents and youth with disabilities, ask
 adolescents and youth with disabilities for their preference
- Types of activities (e.g. physical activity, lecture, group discussion, presentation, reading exercise, writing exercise, handcrafting): ask yourself, "can participants with different types of disabilities (e.g. hearing, seeing, physical, mental) take part in a meaningful way in the activity together with participants without disabilities?" For example, if your activity involves running or playing sports, adolescents and youth with physical impairment might not be able to participate fully. If your activity involves listening to a lecture, adolescents and youth with hearing impairment might not be able to hear well or adolescents and youth with psychosocial impairment might not be able to learn at the same pace as other participants
- Hold a separate activity for adolescents and youth with disabilities if it involves a lot of
 information input as it will likely take longer for them to absorb information. This can
 make them feel more comfortable to ask questions and learn at their own pace.

2.11 Content development: mainstream activities/content for adolescents and young people with disabilities or dedicated activities/content

Activities should include topics such as what disability is, how to identify disability, challenges/opportunities, what inclusiveness means, and how to support people with disabilities.

 When discussing disability issues, activities should include both participants with and without disabilities. It creates an opportunity and a safe space to interact with each other and raise awareness around disability issues. For other topics, each activity needs a separate section dedicated to disability issues, addressing all types of disabilities, so that people can understand disability issues in depth.

2.12 Ensure equal participation for adolescents and youth with disabilities during the activity

Adolescents and youth with disabilities are likely to be shy and may be hesitant to ask for support. Some suggestions to ensure equal opportunities to interact during the activities are listed below:

- Facilitators and people without disability should make the first contact and introduce themselves, ideally before the activity starts
- Create a welcoming atmosphere of trust and inclusion by facilitating informal communication and activities before introducing learning content
- Facilitators should focus on ensuring participants with disabilities interact with others during the activity and during breaktime
- Facilitators should provide constant encouragement to speak up and positive reinforcement when adolescents and youth with disabilities speak
- Ask participants if communication is clear (e.g. ask if your voice is loud enough, if they need more detailed explanation, if the pace is ok, or if they need more breaks)
- Sometimes it is helpful to have a family member and/or OPDs accompany them
- Facilitators should create some ground rules and explain rights and responsibilities (e.g. no discrimination, respect one another, equal rights and opportunity to participation)
- Facilitators should go around and ask each person one by one if they have questions
- Sit close to adolescents and youth with disabilities, get to know them and engage with them during activities. This may require an extra facilitator
- Have a 15 minute break at least every 50 minutes to allow people with disabilities to attend to their needs
- Break up the programme no more than two sessions/activities in a programme before
 and after the lunch break. Finish up by 4pm to have time for individual discussions and
 clarifications with adolescents and youth with disabilities.

2.13 Evaluate if the content of the activity was well-received by adolescents and youth with disabilities

Most adolescents and youth with disabilities are likely to be shy and hesitant to ask questions if having trouble understanding the content. The following techniques are recommended to check their level of understanding.

- Allocate time to get feedback/comments frequently during the activity
- Allocate time for a Q&A session after each session/topic
- Evaluation before and after the activity (use pre and post tests) to see whether their level
 of understanding changes. Make sure to add a check box for disability to the evaluation
 form for activities that include participants with and without disabilities. Participants
 with some types of disabilities might need support from a carer, members from OPDs or
 another person they trust to fill in the evaluation form.

Which sections of these guidelines to consider for your activity

The table below shows which specific sections of these guidelines you should refer to when planning content development, training, or consultation activities with adolescents and youth with disabilities.

Section	Content development	Training	Consultation
2.1		x	x
2.2		х	х
2.3		х	х
2.4		x	x
2.5		х	x
2.6	x	x	x
2.7	х	х	х
2.8		х	х
2.9	x	х	x

2.10		x	х
2.11	x	x	х
2.12		x	х
2.13		х	х

3. BEYOND PRACTICALITY – ACTIONS TO CONSIDER FOR SYSTEMIC CHANGE

These are a few – non exhaustive – elements to consider for those who want to go further, towards systemic participation of adolescents and youth with disabilities.

Building the awareness, abilities and capacities of adolescents and youth with disabilities

Identify issues that need to be addressed within the interest of youth and adolescents with disabilities; create awareness on disability issues among people with and without disability; identify skills and capacities of adolescents and youth with disabilities, support them to develop these capacities, and create an environment for them to practice their skills.

Building the capacity of OPDs and communities on adolescent civic participation

Provide OPDs and communities with training on the rights of adolescents and youth with disabilities; encourage adolescents and youth with disabilities to join OPDs to enhance their diversity perspective.

Setting accessibility standards for institutions and improving accessibility

Show institutions examples of accessible buildings; raise awareness around the importance of accessibility; conduct regular assessments to see whether institutions' buildings are accessible and support them to bridge gaps between the current and desired conditions.

Ensuring adolescents and youth with disabilities participate in planning exercises for institutions

Conduct consultations with adolescents and youth with disabilities on how best they can get involved and participate in planning exercises; set a quota to ensure a minimum number of adolescents and youth with disabilities are included in all planning exercises.

Reflecting a focus on adolescents and youth with disabilities in monitoring and evaluation Include an indicator in monitoring and evaluation plans to track the involvement of adolescents and youth with disabilities in your activities (ideally disaggregated by gender, types of disabilities, and age range); assign someone to focus solely on monitoring adolescents and youth with disabilities' participation in programmes.

Annexes

1. List of OPDs and contacts per municipality

	Umbrella	Vision	Hearing	Physical	Mental/intellectual
Aileu	Asosiasaun Halibur Defisiénsia Raihusar Aileu (AHDRA) • Legal counsel • Economic activity support • Contact number: Abrao Martins (Director) – 7712 2385			T Try Steat	Klinika Uma Ita Nian Santo Francisco de Assis Education Therapy for children with intellectual disability Basic health services Contact number: Guida Xavier Pereira (Motivator Program) 7836 9475 E-mail address: guidaxavierartc@yah
Ainaro					<u>oo.co.id</u>
Atauro					
Baucau	Klibur Aleizadus Timor- Lorosa'e (KATILOSA) Education economic opportunity through handicraft activities		Putri Maria dan Yosep (PMY) Education Therapy for children with hearing impairment		

	 Contact number: Laurentino Guterres (Director) – 3313036 & 7723 3857 E-mail address: glaurentino@yahoo.c om or katilosa@yahoo.com 	 Contact number: Madre Yulia (Superior) – 7747 6476/7333 6478 E-mail address: <u>sranaspmy@gmail.om</u> 	<u>C</u>	
	Associação Clibur da Capacitação da Deficientes de Timor- Leste (ACCD) Capacity building Special education Advocacy Contact number: Tomas Aparicio (President) – 7727 1927 Email address: aaparicio@gmail.com			
Bobonaro	Asosiasaun Halibur Defisiensia Rejiaun Oeste (AHDRO) Capacity building Advocacy Contact number: Sebastiao Gouveia			

Covalima	Leite (Director) – 7782 0909				
Dili	Asosisasun Defisiensia Timor-Leste (ADTL) Advocacy Education and capacity building Economic empowerment Contact number: Cesario da Silva (Director) – 7755 7355 E-mail address: cesarioadtl@gmail.co m Rae's Hadomi Timor Oan (RHTO/DPO) Advocacy Education and capacity building Economic empowerment Contact number: Joaozito dos Santos	Asosiasaun Halibur Defisiensia Matan Timor- Leste (AHDMTL) Advocacy and counselling Research Education and capacity building Cooperative Social promotion and inclusion Handicrafts/Arts Massage centre Contact number: Gabriel de Sousa (Director) – 7844 1946	Klibur Defisiensia Tilun Timor-Leste (KDTTL) Sign language training and interpretation Advocacy Economic empowerment Contact number: Crecencia Madeira de Deus (Director) — 7540 1931	Centru Nasional Rehabilitasaun (CNR) Physical therapy Occupational therapy Prosthesis and orthosis Speech therapy Wheelchair repairs Contact number: 3310 373 or 7713 1205	PRADET Timor-Leste Counselling Psychosocial rehabilitation Contact number: 7724 0331/7804 3103/3321 562 E-mail address Alma Sisters Special school Therapy for children with intellectual disability Contact number: Madre Udis (Superior) – 7747 1552/3313 024 E-mail address: alma dili@yahoo.co m

	(Director) – 7732 9907/3310 540 • E-mail address: <u>joaozito.rhtodpo200</u> <u>6@gmail.com</u>		
Ermera	Forum Juventude Defisiensia Ermera (FJDE) Advocacy Economic empowerment Contact number: Marcos da Costa – 7557 9612		
Lautem			
Liquica	Klibur Domin TB treatment Therapy for people with motorics Psychosocial therapy Contact number: Joaquim Freitas Soares (Director) – 7723 2016 E-mail address: kliburdomin@gmail.c		
Manatuto			Centro Sao João de Deus Counselling

		 Mental health therapy Contact number: Titu Alves (Paramedic) – 7838 1321/7734 7775 E-mail address: cassidlaclubar@sapo.tl
Manufahi	Fuan Nabilan	
	Capacity building	
	Contact number:	
	Joaquim Tavares	
	(Director) – 7740	
	3856/7728 0035	
	E-Mail address:	
	fuannabilan2001@g	
	<u>mail.com</u>	
Oecusse	Sentru Defisiensia	
	Enclave Oecusse	
	Education	
	Capacity building	
	Advocacy	
	Economic	
	empowerment	
Viqueque	Sentru Defisiensia Sen-	
	Fronteira Uatucarbau	
	(SEDU)	
	Information centre	
	Mental health	
	services	

Social assistance
centre
Contact number: Dr
Heldegar Martins
(Founder) – 7789
7908
E-mail address:
<u>eldegarlopesmartins</u>
@gmail.com

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