



Citizen Voice and Action
for Disability
Practice Notes

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Cover photo: Noor Omar Mohammed, a Somali refugee living with a disability in Kakuma, Kenya, is a small enterprise business owner and member of a CVA working group in Kakuma Refugee Camp, Kenya. He is also a member of the Voice of Disabled Peoples Association in the camp.

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Introduction

Citizen Voice and Action (CVA) is a local level advocacy methodology that transforms the dialogue between communities and government in order to improve services, like health care and education, which impact the daily lives of children and their families.

The goal of Citizen Voice and Action is to improve the accessibility and quality of public services. Through collaborative, non-confrontational dialogue between service users, government and providers, users are empowered to monitor and seek accountability for service delivery and to take collective responsibility for services. CVA is based on the view that each citizen has the right to hold to account his or her government for fulfilling its commitments.

This field guide is intended to help you to use CVA to address issues related to disability, as a supplement to existing resources on CVA implementation that can be found on [WVCentral](#).

Why is it important to address issues around disability using CVA?

Persons with disability, who make up to 15% of the world's population, have rights that need to be protected | Persons with disability in most countries are protected by legislation that has been developed in response to the country's ratification and signing of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).¹ The UNCRPD guarantees equal access to education, health, social and other services for persons with disability. The UNCRPD also mandates governments to provide services that meet the specific needs of persons with disability including rehabilitation services and assistive technology. Governments have also been encouraged to commit to providing assistive technology such as wheelchairs, hearing aids, prosthetics and crutches as listed on the World Health Organization priority assistive products list on assistive technology provision.²

Children and other persons with disability in communities where WV works are often excluded from decision-making and advocacy efforts | Persons with disability are stigmatized in most countries, even if they are wealthy. This means that their needs are often ignored in the development of legislation, policy, budgets and in the provision of services. Even services designed for persons with disability are often designed without their engagement. [Citizen Voice and Action \(CVA\)](#). World Vision's proven approach to social accountability, provides a structure to support the engagement of persons with disability to take a leadership role. CVA also provides a way to collect data on issues of persons with disability's access to rights and services that isn't typically available from government data. This data can then inform better decision-making.

¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

² https://www.who.int/phi/implementation/assistive_technology/EMP_PHI_2016.01/en/

Who should be engaged in CVA for disability?

This will depend on your target level, from community up to national level. Generally, CVA should bring together people, service providers and government decision-makers who can make changes to budgets and plans. Three groups are essential:

1. Persons with disabilities (PwD) – with representatives of different types – those who have problems seeing, hearing, communicating and with mobility, mental health or intellectual disability.
2. Disabled person organizations (DPO) – organizations run by persons with disability, with organizations representing different types of disabilities.
3. Service providers (governmental, non-governmental, private) - those responsible for providing disability services including local and national representatives of Ministries of Health, Education, Social Protection as well as any cross-cutting disability committees that oversee the local or national level implementation of the UNCRPD-related legislation across different ministries;

Additionally, these other groups can be engaged:

- Disability-focused organizations – these are run by persons who don't have a disability but are focused on disability issues such as Humanity and Inclusion, CBM, Leonard Cheshire, Light for the World, Sightsavers
- Human rights protectors – government (ombudsman) and non-government organizations that focus on protecting citizens' rights that can be engaged to support disability rights.

In El Salvador, persons with disability were paired with existing CVA groups that had been focused on youth issues. The existing groups were passionate advocates and helped empower members who have a disability. In Kenya, Nicaragua, and Romania, groups included a range of participants, with people with disabilities and their families taking priority along with community members who had previously worked on CVA initiatives. Other group members included teachers, administrators, church leaders, government officials, and social workers. In India and Georgia, the CVA groups consisted entirely of persons with different disabilities and disabled person organization (DPO) representatives. This had the benefit of facilitating the formation of a local DPOs, or capacitating existing DPOs, but did not provide the contact with service providers or other community members.

How can you integrate disability within CVA?

There are two main ways:

1. **Integrated into existing CVA programs** by making sure that any CVA action related to a particular sector (health, education, WASH, etc.) ensures that persons with disabilities' rights and access to services is incorporated into the CVA process. Persons with disabilities, disabled person organizations and disability service providers would need to be included in this process. In order to do this, you should:
 - a. Integrate government standards for services for persons with disability and their application within the 'Monitoring Standards' tool in CVA – See detailed CVA

Guidance and shorter field guide at (<https://www.wvi.org/local-advocacy/publication/citizen-voice-and-action-field-guide> and <http://www.kwantu.net/resources-1/2015/11/25/citizen-voice-and-action-guidance-notes>)

- b. disaggregate data on access and quality of services to ensure that the views of persons with disability are identified
 - c. organize a sub-group on disability that could report back to the main group within the scorecard process
 - d. ensure representation of persons with a disability, their representative advocacy groups as well as any government officials with responsibilities for disability within 'community gatherings'.
2. **As a standalone CVA and disability program** that brings together groups focused on disability, persons with disabilities, DPOs, disability service providers, and potentially disability-focused organizations and human rights protectors. This program would focus exclusively on services and rights for persons with disability across different sector areas.

In either case, there are some main steps to take:

1. Identify a disabled person's organization who can work with you to define:
 - a. if your country has signed and ratified the UNCRPD and the optional protocol
 - b. if government legislation has been developed in line with the UNCRPD
 - c. the rights and services outlined for children and adults with disabilities
 - d. any gaps in the rights and services compared to the legislation or to the UNCRPD
 - e. existing priorities for advocacy among DPOs and persons with different kinds of disability (as wheelchair users may have very different priorities for example, to persons who are deaf)
 - f. existing data on access to services and rights for persons with disability
2. Develop a set of accessible information materials with DPOs that can inform communication around rights and services for persons with disabilities
3. Test those materials with communities to ensure that the language used is understandable and is positive about persons with disability (many cultures have very negative words for persons with disabilities).
4. Identify relevant indicators to support consistent monitoring (see Annex 3)

What changes do you need to make to existing CVA programming to make it more accessible for persons with disabilities?

The following steps are key to ensuring your program is accessible:

- **Engaging persons with different types of disability in the planning and implementation processes** – this will make sure that you can understand and address all barriers to participation for persons with different types of disability
- **Communication in accessible formats** – conducting home visits to those who can't access community venues, producing braille materials, providing information in sign language, using simplified language versions with images

- **Adapting the workshops** – please see Annex 1 for details on how to do this
- **Enhancing the image of persons with disabilities** – In El Salvador and Nicaragua, CVA groups used inclusion festivals and International Disability Day (December 3) to raise awareness of disability rights and show persons with disability in a positive way.
- **Challenging staff, service provider and community attitudes to disability** – using activities to challenge negative attitudes as outlined in Annex 2.

Tip: Involving children in CVA efforts can be an effective way to break down attitudinal barriers to disability inclusion. In Romania, World Vision's registered children brought awareness messages back to their friends and families, acting as a catalyst for change.

How has CVA been used to address disability issues in our programs?

CVA has been used extensively in two standalone programs but has had limited use within mainstream CVA programs:

The USAID-funded **Training, Economic Empowerment, Assistive Technology and Medical/Physical Rehabilitation Services (TEAM) project** engaged 2,749 persons with disability in CVA processes in Colombia. The project and the disability officer from the Municipal Health Secretariat informed PwD and service providers about relevant legislation and national service delivery standards relating to health. By using the disability officer as a trainer, this strengthened the officer's position as a bridge between service providers (many of which were located outside the municipality) and community members and their role in guaranteeing the quality of service provision.

The 18 CVA groups each produced an action framework. They prioritized the most frequently violated rights for people with disabilities including delays in receiving care, the shortage of available appointments with health specialists, limited accessibility in parks and other community settings, and the limited opportunities for employment and income generation. Local authorities listened to CVA groups and expressed verbal commitment to addressing the issues raised. A total of 175 actions were directly attributed as responses to CVA processes. Groups then monitored progress towards these commitments. Perhaps the greatest impact of the CVA groups, was the strengthening of relationships around disability, resulting in greater solidarity, understanding and support.

“The TEAM project and CVA helped a lot of people to understand, and to energize and gather people through the Local Action Boards. I think it was a success.”

–Jorge, project participant, Barranquilla

Within the **ACCESS Wheelchair program**, that covered India, Romania, Nicaragua, El Salvador and Kenya, each CVA group developed a community action plan and use community scorecards. Common themes across communities included:

- Access to Disability Certification: Kenya, India, and Romania
- Accessible Infrastructure: El Salvador, Nicaragua, Kenya, and Romania

- Accessible Education: [El Salvador](#), [Kenya](#), and [Nicaragua](#)
- Accessible Transportation: [India](#) and [Nicaragua](#)
- Access to Medicines: [Kenya](#) and [Nicaragua](#)

The program achieved the following notable results:

El Salvador	Municipal ordinances on disability inclusion developed in 4 municipalities: Armenia, Santa Elena, San Vicente and Ozatlán. These municipal ordinances were the first in El Salvador, and addressed employability, rights promotion, accessibility, access to education and quality health care.
India	100 people obtained disability certificates. Two people with disabilities obtained train passes and 22 enrolled for bus passes. 250 people with disabilities enrolled in health insurance. New DPOs were created by CVA groups. National findings on needs of persons with disabilities were published and disseminated.
Kenya	In Kiambogoko, the sub county administrator pledged to reserve 5% of all jobs for qualified PWDs. In Osiligi, administrators reserved market stalls for PWDs and included accessibility in infrastructure budgets. Ramps and accessible toilets were constructed in schools, medical facilities, and government offices including Nakuru County Hospital, Chiefs' offices in Kiambogoko, Osiligi, and Katito, Olepolos Primary School, and A.I.C. Birsil Health Centers.
Nicaragua	Wheelchair ramps built at public institutions and in public parks. Anti-bullying campaign held in 26 schools. 410 health workers, mayoral representatives, municipal court authorities, education officials, and academics trained in disability inclusion. Ministry of Education committed to training 500 teachers in disability inclusion.
Romania	Local authorities built 24 ramps and access routes to make beneficiaries' homes accessible, made one bathroom and one public recreational area accessible, facilitated transport to specialized medical services, and protected clients' legal rights. Communities demonstrated a more positive attitude to persons with disabilities and wheelchair users increased their social interactions.

Annexes

Annex I | Pointers for facilitators of focus groups/group interviews to include children and adults with disabilities

Facilitators are key to enabling a safe, friendly and inclusive environment for focus group/group interviews and meetings. However, not all facilitators are trained or confident in dealing with participants with disabilities. This supplementary guidance may be helpful in building facilitators' confidence to turn the workshop into a more meaningful learning experience for everyone.

BEFORE THE WORKSHOP

- Provide participants with a list of accommodations that can be made available and ask them to identify which they might require. These could include: sign language interpretation, wheelchair accessible venue and toilets, adapted transport, captioning, enlarged text on printed material, electronic versions of materials to support screen readers, being accompanied by an aide or family member, allergy free food; vegan/vegetarian diet; fasting diet etc. This could be accompanied by a prior assessment of participants (see below).

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response category

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

- Do a prior assessment of participants to determine their unique needs including those with disability. Below is a simple checklist of what could be considered in the pre-workshop participant assessment (Adapted from Light for the World, 2017):
 - Determine what are the most important difficulties that people encounter? (The Washington Group Short Set of questions below may be helpful)
 - What are people able to do, what not?
 - Discussions with staff (individuals/groups, all levels) and other people who have engaged in similar workshops
 - Learning/evaluation reports from previous trainings/workshops
 - Observation of people (individuals/groups, all levels), and of their situation

- Adjust the pace, length/duration of the workshop. Ensure there are regular breaks.
- It is important that people who are less literate or those with mild to moderate intellectual impairments can catch up with the sessions. The key is using simple language, short messages, repetition and visual aids.
 - Make reasonable accommodations (arrange sign language interpreter, easy read/big print materials, audio, pictures, role play, etc.) to increase ease of learning for participants with different abilities. An accompanying person may be needed to assist a participant with disability.
 - Plan for a suitable venue that is accessible to participants, including travel arrangements and support. Appropriate signages, lighting, seating and room layout are also important to consider.
 - Commission DPOs (Disabled persons' organisation) as a resource/ trainer if possible as they will ensure the workshops are more accessible for all participants

DURING THE WORKSHOP

- Establish ground rules among participants to ensure participation is meaningful, inclusive, safe and fun
- Ensure that persons who are blind or have visual impairment receive a tour of the venue
- Reserve seats for persons with reduced mobility closer to doors and those with hearing and visual impairments closer to the facilitators
- Build the confidence of participants
- Be aware of non-verbal cues. This is very important especially when working cross culturally since gestures and expressions can be understood differently.
- Use appropriate ways of getting feedback during the activity – graffiti walls (where people can write their comments), parking lot (for people to place sticky notes), 'moodometer' (using emojis to express how they feel), blogs, journals
- Conduct quick post-session debriefs with participants to monitor and solicit feedback to improve sessions.

Coaching participants with disabilities

Participants with disability may require extra support as they learn from the sessions. If you are unsure about how you can support someone, speak to them informally at the end of the first session and ask them if there's anything that you can do to improve their learning or participation. Each person has their own specific needs.

Below are some tips for communicating with persons with different impairments.

Communicating with persons with different impairment

(Adapted from Bridging the Gap: Inclusive and Accessible Communication Guidelines 2018)

Persons who are deaf or hard of hearing

- To get the attention of a person, wave your hand or tap on the person's shoulder lightly when culturally appropriate.
- Follow the person's cues to find out if she/he prefers sign language, gesturing, writing or speaking.

- Look directly at the person and speak clearly, slowly and expressively without overreacting/overemoting to establish if the person can read your lips
- Speak in a normal tone of voice
- Keep your hands and food away from your mouth when speaking
- Try to eliminate background noise
- Use written notes to facilitate communication if the person is literate
- Encourage feedback to assess clear understanding.
- If you have trouble understanding the speech of a person who is deaf or hard of hearing, let her/him know politely
- Learn some basic signs yourself and encourage the group to practice them and use for direct communication with participant)

Persons who are blind or partially sighted / with visual impairment

- Always identify yourself and others who may be with you. When conversing in a group, remember to say the name of the person to whom you are speaking to give vocal cues
- Speak in a normal tone of voice
- Indicate when you move from one place to another and if you leave or return to a room.
- Let the person know when the conversation is at an end
- When you offer to assist someone with a vision loss, allow the person to take your arm to better guide this person
- When directing, use specifics such as "left at 2 meters" or "take three steps to your right"
- When offering seating, place the person's hand on the back or arm of the seat
- Read anything that is written, this will also help those participants who are not literate

Persons with speech impairment

- Give whole, unhurried attention when talking to a person who has difficulty speaking
- Allow extra time for communication
- rather than correcting. Be patient, do not speak for the person
- If necessary, ask short questions that require short answers or a nod or shake of the head
- Keep your manner encouraging

Persons with intellectual disabilities

- Take the time necessary to ensure clear understanding and give time to put the thoughts into words, especially when responding to a question
- Formulate simple sentences and repeat as necessary
- Use precise language incorporating simple words. Avoid the use of directional terms like right-left, east-west, etc.
- Use pictures and visuals
- When asking questions, phrase them to get accurate information. Verify responses by repeating each question in a different way
- Give exact instructions: for example, "Be back from lunch at 12:30," not "Be back in 30 minutes"
- Do not give too many directions at one time

Persons with reduced mobility/wheelchair users

- Talk directly to the person and try to be at his/her eye level, but do not kneel. If you must stand, step back slightly so the person doesn't have to strain his/her neck to see you.
- When giving directions to people with mobility limitations, consider distance, weather conditions and physical obstacles such as stairs, steep hills, road condition
- Always ask before you move a person in a wheelchair
- If a person transfers from a wheelchair to a vehicle, toilet, etc., leave the wheelchair within easy reach.
- Always make sure that a chair is locked before helping a person transfer.

AFTER THE WORKSHOP

As you finish the workshop, remember to appreciate everyone's participation and contribution. Seeking their feedback on the overall aspects of the workshop will also help to improve future sessions.

- Conduct a post-workshop evaluation, including questions about the ease of participation for persons with disability
- Consider working with organizations (e.g., DPOs) with specific skills on working with people with disability in future activities



Annex 2 | Suggested activity to challenge negative attitudes

Research³ suggests that it is hard to completely change negative attitudes toward disability in just one intervention as they stem from different sources. These negative attitudes vary according to context and are generally less severe towards persons with minor or moderate impairments and include:

- A belief that a disability results from sin by the parent or the individual and that persons with disability are dangerous
- Inherent discrimination towards minority groups
- Socio-cultural norms that say that people need to be physically “whole” and value wealth and status (which are often unattainable for persons with disability)
- A conflict or uncomfortable situation resulting from the person's inaccurate expectations of persons with disability (they will be passive, because they can't do one thing (hear, see) they must be stupid and can't do anything, they shouldn't have sexual relationships or get married, they shouldn't have opinions) and the reaction of the person with disability to that expectation. This conflict may lead to a person seeing persons with disability as ungrateful or aggressive.
- Being revolted or shocked by the disability – an amputation, skin condition or difference in body from the ‘norm’
- Fears around an individual's mortality and health that may stem from being around someone with a disability

We therefore recommend a combination of interventions to address attitudes:

- I. Behaviour change messaging – by informing and persuading
 - a. Inform – provide information about persons with disabilities, that they have rights as outlined in your country's legislation - to go to school, access services, get married; and about the different causes of disability to clarify that sin is not a cause.
 - b. Persuade – persuade people to see that persons with disability are persons that have rights and are valuable members of the community. It is helpful here to include passages from religious texts that provide a positive view of persons with disability and to help people to understand the barriers towards persons with disability. A great tool for identifying barriers are the Wall and Game of Life⁴ activities that are part of WV's Travelling Together – a one-day training on disability issues. The games are attached at the end of this document. Ideally, messaging should be developed based on barrier analysis.⁵

³https://www.researchgate.net/publication/232588909_Societal_attitudes_toward_disability_Concepts_measurements_and_interventions

⁴ <https://www.wvi.org/disability-inclusion/publication/travelling-together>

⁵ <https://coregroup.org/resource-library/a-practical-guide-to-conducting-a-barrier-analysis/>

2. Facilitate Contact in a meal or collective task such as the CVA process of developing joint plans – bringing persons without disability who have received behaviour change messaging together with persons with disability. Research has shown that this is easier when:
 - a. The persons with disability have a higher status, potentially resulting from the research they have conducted as part of the CVA process
 - b. The activity is facilitated by World Vision or other respected group, such as within a CVA training program
 - c. The activity is voluntary, enjoyable, and benefits everyone



Annex 3 | Suggested indicators

The following indicators could be monitored in either integrated or standalone disability and CVA programs. Indicators will need to vary depending on the rights and services for each country. All existing CVA indicators can be assessed by persons with disability and compared to other groups to identify differences in access to services and outcomes of services. To identify the numbers of persons with disability accurately, the Washington Group short set of questions⁶ should be used for adults, these are:

1. Do you have difficulty seeing, even if wearing glasses? a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
3. Do you have difficulty walking or climbing steps? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
4. Do you have difficulty remembering or concentrating? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
5. Do you have difficulty (with self-care such as) washing all over or dressing? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

For children, the UNICEF/Washington Group Measurement of Child Functioning module⁷ should be used. Indicative Indicators are outlined by sector.

Education

- # or % of children with disabilities attending school
- # teachers trained in special education or to support inclusive education
- # schools with wheelchair accessible latrines
- Blind children can learn braille in the school and access braille learning materials
- Deaf children can learn sign language and can receive instruction in sign language in school
- Parents of children with disabilities participate in parent teacher association meetings
- Schools or communities provide unpaid additional support for learners who need it

Health

- Availability of rehabilitation services – physical therapy, occupational therapy, speech therapy

⁶ <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/>

⁷ <https://data.unicef.org/resources/module-child-functioning/>

- Availability of assistive devices – wheelchairs, hearing aids, glasses, crutches and others
- Health information is accessible to the blind and visually impaired, the deaf and hearing impaired and in simple language for persons with intellectual impairments
- General health services including reproductive health services are available to persons with disability

Child protection

- Mechanisms are in place to identify children with disabilities who are vulnerable
- Mechanisms are in place to refer children with disabilities to service providers that can meet their needs

Water, Sanitation, and Hygiene

- Latrines are accessible to wheelchair users
- Water access points are accessible to wheelchair users
- Provision is made so families of persons with disabilities can access water