The role of community-based non-specialists (CBNS) in providing holistic wheelchair services
The role of community development organizations in providing holistic wheelchair services

This report uses the definition of a wheelchair provided within the WHO Wheelchair provision guidelines.

A wheelchair is: inclusive of all types of wheeled mobility devices including manual, power, power assisted, wheelchairs, tricycles and scooters, and essential components or features such as wheelchair cushions and postural supports.

An appropriate wheelchair: meets the user’s needs and environmental conditions, provides proper fit and postural support, is safe and durable, is available in the country; and can be affordably obtained and maintained and provided in country.

Community-based non-specialists (CBNS) are individuals based in communities who do not have any prior training or experience in wheelchair provision. These could include community health workers, child protection structures, teachers, nurses, doctors, social workers, organizations of persons with disabilities, formal and informal groups, faith groups and community volunteers.
In October 2017 World Vision produced a report entitled “The 8 Steps+”, outlining the role of community development organizations in providing holistic wheelchair services. This report was based on lessons learned within the ACCESS Wheelchair program funded by the United States Agency for International Development (USAID). This program brought together technical organizations including Motivation Charitable Trust, United Cerebral Palsy Wheels for Humanity and Motivation Romania Foundation with World Vision. This report built on the World Health Organization (WHO) wheelchair provision 2008 guidelines that outlined 8 steps critical for effective provision. It added steps that World Vision and other organizations working at community level can support to enhance the quality of life for wheelchair users. The revision of the WHO guidelines in 2023 to a four step approach, led World Vision to develop a revised report that reflects our ongoing learning.

The first report focused on community development organizations and their role in working with specialist wheelchair providers. This revised document recognizes that there are different actors at community level that can and should play a critical role in providing holistic wheelchair services.

It seeks to build on the observation in the revised WHO guidelines that “the involvement of mid-level and community-level personnel could expand the workforce who are able to deliver identification, referral and service steps.”

These actors could represent government, private sector, organizations of persons with disabilities, faith groups as well as community development organizations. While some of these actors were outlined as stakeholders within section 2.7 of WHO’s wheelchair provision guidelines, this report seeks to go further in defining roles based on World Vision’s experience. The report provides a vision for the role community-based non-specialists (CBNS) can play when working on wheelchair provision. Not all CBNS will have the same resources, so partnerships will be needed to ensure that wheelchair users and potential users receive the services they need. A strong preference is for CBNS to be part of the health service delivery mechanism, so that wheelchair services are integrated into universal health coverage. World Vision works with as many as 200,000 community health workers around the world and they are potentially ideal CBNS, if this role can be integrated into their already extensive list of duties.

At the 2022 Global Disability Summit, World Vision committed to increasing the number of children with disabilities that it serves by over five times over the next five years. As a community-based organization, World Vision doesn’t have the skills to meet the needs of all these children alone. This report is intended to provide guidance on how organizations working at community level can work with wheelchair providers to provide wheelchairs and other assistive devices to the children and adults who need them. The examples are
The role of community development organizations in providing holistic wheelchair services

The importance of appropriate wheelchairs

Access to an appropriate wheelchair is a human right recognized in the right to personal mobility outlined in the UN Convention on the Rights of Persons with Disabilities which 187 states have ratified and are now party to. Access should be part of universal health coverage, equitable and place people at the center.

In the past, many wheelchairs were simply distributed and were not provided according to the WHO guidelines. This meant that people received wheelchairs that were not appropriate – that the wheelchair was not provided based on the user’s needs and environment, fitted correctly and follow-up services were not available.

This has led to high rates of wheelchair abandonment and resulted in life-threatening secondary complications for users. The most common secondary complications from improperly fitted wheelchairs and lack of 24-hour postural management are pressure sores, spinal deformities, shoulder injuries and contracture (tightness in the joint that makes it impossible to straighten limbs). Pressure sores can be fatal. Other injuries severely restrict the user’s function, quality of life and cause pain. This can be prevented by providing wheelchairs in line with the four steps in the WHO guidelines. The provision of a wheelchair or multiple wheelchairs (as a user may need more than one kind) by itself does not address all the user’s needs. They also need to be able to access their home, community, and transportation. They need to be able to go to school or earn an income. This requires physical barriers to be removed and for attitudes to be changed among the user themselves and the broader community so that the wheelchair user can live life to its fullest.
World Vision seeks to empower local communities to sustain their own development. We work with a range of people that could act as CBNS including community health workers, child protection structures, teachers, nurses, doctors, social workers, organizations of persons with disabilities, formal and informal groups, faith groups and community volunteers. Ideally, CBNS should be part of the health system to ensure that wheelchairs are integrated into universal health coverage. If they are not, they should work together with the health system. The key requirement is that CBNS are based in the community, are respected by the community and are willing to commit to identifying and supporting the needs of wheelchair users. CBNS do not need to have prior expertise in disability or rehabilitation or assistive devices. CBNS will need some support to understand the process and the tools used to manage the process outlined here.

This could include training, including the ISWP’s basic level training and the WHO’s training in assistive products, mentors and communities of practice. CBNS were not explicitly mentioned in the new WHO guidelines but could include organizations of representative groups, local governments, service personnel and international agencies mentioned in section 2.7 on the role of stakeholders.
04 ASSURING QUALITY

The use of minimally trained CBNS represents a significant risk in ensuring effective identification, referral, and follow-up. For this reason, World Vision has developed an app-based disability case management system that works both on-line and off-line. This allows World Vision to use people who have experience gathering data using a phone or tablet to be guided in their data collection using skip logic so that the questions are specific to the situation for that person. The data then provides specific recommendations for referrals or other actions for the individual and their family. Telehealth could also be used for more experienced staff to support CBNS or to consult directly with a wheelchair user or potential user.

A program manager can assess the quality of data collected and provide additional support to CBNS where the data quality is lower. The case management system has been used in two countries and adjustments are being made to enhance its functionality based on user feedback. The case management system or similar systems developed to support rehabilitation provision such as the EI app could also be used to address the WHO wheelchair provision guidelines recommendations at system level to support 6. seamless referral and access and data to inform 7 systematic evaluation.

05 HOW CBNS CAN ADDRESS KEY BARRIERS AROUND WHEELCHAIR PROVISION

The use of CBNS addresses some key barriers to increased access to wheelchairs that were identified within the Wheelchair provision guidelines. It addresses barriers around people:

- Individual – by supporting individuals to remove personal barriers including age, gender, type and extent of mobility impairment, living environment, socioeconomic and education status
- Stigma – by working at community level to reduce stigma towards persons with disabilities and wheelchair users.
- Information – by informing persons who may benefit from wheelchair provision about service benefits and availability and about wheelchair user groups and other available support.
- Participation – by including wheelchair users in wheelchair and broader health service delivery and in feedback mechanisms.
And provision:

- **Awareness** – by working with wheelchair providers to demonstrate the value of appropriate wheelchairs for their clients.
- **Operating in silos** – by facilitating linkages and referral systems between health providers at primary level and wheelchair provision at secondary and tertiary level.
- **Fragmentation** – by supporting a case management system that ensures that delivery steps are met.
- **Access** – by identifying and addressing barriers to wheelchair services, supporting outreach models and telehealth or transport costs for families to access services equitably.
- **Timeliness** – by providing data on unmet needs that can drive resource allocation.
- **Waste** – by identifying wheelchairs that have been abandoned and need repair or refurbishment and working with wheelchair providers to establish systems to address these issues.
- **Follow-up** – by identifying and addressing barriers to accessing follow-up services, providing better community-based follow-up with re-referral to the wheelchair provider as needed to prevent abandonment and improve maintenance and re-use.

CBNS can also improve provision by facilitating feedback from service users that highlights strengths and weaknesses in the system.

And policy, World Vision and other CBNS may have strong ties to government at national level and local government level and can advocate for improved policies and funding. World Vision has used its social accountability methodology, Citizen, Voice, and Action (CVA) for this purpose in two programs.

More details on how CVA has been used to support persons with disabilities can be found here: Practice Notes: [Citizen Voice and Action for Disability | Social Accountability | World Vision International (wvi.org)](https://www.wvi.org).

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 persons with disabilities 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 USAID-funded ACCESS Wheelchair program, that covered India, Romania, Nicaragua, El Salvador, and Kenya, mobilized wheelchair user CVA groups, to develop a community action plan and used community scorecards to assess the quality of services. Common themes across communities included accessible infrastructure, transportation, education, and disability certification.
World Vision ensures that any partner organization follows the WHO service level recommendations (see below) for wheelchair provision, staff have the appropriate level of education for the required devices (including ISWP basic and intermediate-level training), and they have the correct range of devices.

Ideally, they will have physiotherapists or other trained rehabilitation professionals who can objectively identify those who can benefit from wheelchair provision to minimize the need for additional referrals and the risk of communication breakdowns. World Vision refers organizations to the International Society of Wheelchair Professionals (ISWP) for support if they are not able to meet the required standards.

**WHO SERVICE LEVEL RECOMMENDATIONS**

1. **Select:** Wheelchairs must be provided using a process of individual assessment and selection

   Individualized assessment and selection are the process by which a wheelchair user, in collaboration with appropriately trained personnel, defines their physical, functional, environment and lifestyle needs and preferences; and then selects the wheelchair and features that best meets those needs.

2. **Fit:** Wheelchairs must be prepared and fitted to each person based on their individual assessment

   Preparation involves assembling the wheelchair and any accessories before fitting. Fitting involves adjusting and modifying the wheelchair, wheelchair cushion, postural support devices, and any other accessories to achieve optimal fit, mobility, postural support and function.

3. **Train:** Training must be provided for wheelchair users and those who assist them to enable maximum use

   Training in skills including transferring in and out of the wheelchair and wheelchair mobility, how to use the components, how to guide others in assisting them, as well as wheelchair maintenance and simple repairs, will enable wheelchair users to gain maximum benefit and avoid harm.

4. **Follow up:** Ongoing follow up is an integral part of wheelchair service delivery and should be offered and available to all wheelchair users throughout their life

   Follow up has two components: review and remediation. Review involves collaboration between a wheelchair user and service provider to identify how well the wheelchair continues to meet the wheelchair user’s needs. Remediation involves addressing and resolving any identified problems.
Once a partner has been identified, it is critical to have clear agreement to ensure that the wheelchair provision process functions smoothly for wheelchair users and potential users. These should outline the roles and responsibilities for each party including:

1. Roles of each partner including which partner will be covering specific costs (transport, travel-related costs, cost of device, time of provider etc.)
2. Process for referral including contact persons, information provided, necessary forms or data.

07
THE ROLE OF COMMUNITY-BASED NON-SPECIALISTS (CBNS)

This outline of the role is based on World Vision’s experience in working with wheelchair providers. Community-based non-specialists (CBNS) are critical in providing continuity of support to individuals throughout the elements of the process of wheelchair provision. The diagram below outlines the process, with steps in orange those that CBNS can be heavily engaged in. Wheelchair provision is the role of the specialist wheelchair provider partner and should be carried out according to the 4 Steps within the WHO guidelines.

Empowerment cuts across the process. Follow-up is part of the 4-Steps and can be the joint responsibility of wheelchair provider and CBNS. The use of a shared case management system across different actors can enhance the process.

- Identification of persons who may benefit from using a wheelchair. Often possible users may be far away from wheelchair providers and unaware of the existence and value of wheelchairs and their right to receive wheelchairs. Wheelchair providers don’t often have the funding and networks to reach remote areas to provide equitable access.
- Referral of persons who may need a wheelchair to access equitable wheelchair services. Where possible, CBNS can facilitate outreach services so people can receive services in their community or at home. If this is not possible, CBNS may need to provide financial support or specialized transport.
- Follow-up to see if the wheelchair is having the desired impact on the lives of users. The wheelchair is only a tool to support a person’s mobility and may not result in
improvements to their lives if they are unable to use it, if their home and outside environment is not accessible using their wheelchair and if stigma is preventing their inclusion in their household, community, and society. CBNS can understand these remaining barriers and work with specialist wheelchair providers to remove them. CBNS can also conduct basic clinical follow-up using the questions in Annex 5. They can also facilitate telehealth to allow for remote follow-up from wheelchair providers where possible.

- Empowerment of wheelchair users and potential users by providing them with information and support to access services and by creating an inclusive, enabling environment in their households and communities and linking them to organizations of persons with disabilities and wheelchair user groups who can advocate on their behalf.

**DETAILED GUIDANCE ON THE ROLE OF CBNS WITHIN THE PROCESS**

**a. Identification**

World Vision has worked with volunteers, community health and education workers and staff working at community level to support the identification of children who have disabilities, including those that might need a wheelchair. To minimize the number of children who are identified by CBNS and referred but don’t need any kind of rehabilitation or assistive device, we use a two-step process with an optional third step as shown in Figure 1. No process of identification is perfect, particularly one using non-specialists, but this process shows promise as a way of ensuring that children with moderate to severe mobility impairments are seen by rehabilitation professionals who can assess their needs more accurately. This could be adapted to assess adults with disabilities.

**Figure 1 - the three sub-steps within the identification process**

1. Identifying children with mobility issues using question-based tools

2. Identifying extent of mobility issues with follow-up questions

3. Child specific information with video, photos, measurements
1. **Initial identification:** World Vision uses three tools at this stage depending on their age. They are embedded in the case management application:

- **For children aged under 2:** a contextually appropriate ages and stages tool such as the Trivandrum development scale, the cDMAT that assesses a child’s function against anticipated function for children of that age. To assess mobility impairments, this could include bearing weight on legs, standing alone, crawling, pulling up to stand, stand when supported. For countries where there is no defined tool, World Vision has included one question on movement per sub-age group and this list can be found in Annex 1.

- **For children aged 2-4:** the Child Functioning module (see Annex 2): The module has 16 questions including CF7: “Does (child) use any equipment or assistance for walking” and then identifies with questions CF8-10 if the child, with or without equipment has difficulty walking with response options of no difficulty, some difficulty, a lot of difficulty or cannot do at all. If responses are a lot of difficulty or cannot do at all, this triggers more questions on their mobility (Annex 4). Additionally, CF11 identifies if children have difficulty picking up small objects with their hands. This may provide some indication of the type of device that might work for them.

- **For children aged 5-17:** the Child Functioning module (see Annex 3). The module includes CF7 “Does (child) use any equipment or assistance for walking”. Questions CF8-13 are related to walking and if the child can walk 100 meters or 500 meters on level ground with and without equipment or assistance with response options of no difficulty, some difficulty, a lot of difficulty or cannot do at all. If responses are a lot of difficulty or cannot do at all, this triggers more questions on their mobility (Annex 4). CF14 asks about their ability to feed and dress themselves. This may provide some indication of the type of appropriate device.

2. **More detailed identification:** If a child is positive for a mobility impairment from the initial identification this triggers additional questions which can be shared with a physiotherapist or other trained rehabilitation professional for them to assess if it is likely that the child will need a wheelchair. See Annex 4 for a list of these questions. If they already use a device, then additional questions will be triggered on the kind of device, when it was provided, how it is used and the level of function of the device. See Annex 5 for a list of the questions for a wheelchair user. There are also questions related to the home environment, some of these would be supportive of understanding their mobility needs and are outlined in Annex 7.

3. **Further identification:** To improve identification further, the physiotherapist or other trained rehabilitation professional can request the community-based non-specialist to collect additional information. Video or photographs of the child, their home and community environment can be taken that might help the therapist to understand the child’s needs. If it is likely that the child will need a wheelchair or other assistive device, specific measurements can be taken for the child so that an appropriate device can potentially be fitted during an initial visit.
b. Referral

In the World Vision case management system, referral is triggered automatically by responses to questions at the identification stage. Ideally, the referral will be to an organization that has physiotherapist or other trained rehabilitation professional and wheelchair technician capacity (see partner section). Depending on the organization’s situation, World Vision may contribute to the cost of the devices, travel-related expenses so the organization can travel to the child’s home and community. As families that include a person with disability are more likely to be living in poverty, CBNS may need to pay for travel expenses for the child and a caregiver to travel to receive the wheelchair service.

c. Follow-up

In the World Vision case management system, CBNS will set a deadline for follow up within the system. The initial follow-up will occur between one week and three months and will continue as long as needed. During follow-up, CBNS will make sure that the referral established in the prior visit was made and the service received. If a wheelchair service is received, they will record the type of assistive device provided, the date provided and if training and follow-up were provided. Additional questions will assess the functionality of the device, how it is being used, how often it is used and how it is impacting school attendance, their participation in community events, their mobility around the house, school, and community. See Annex 5 for the questions related to wheelchair use and Annex 6 for referrals that are automatically generated depending on responses to those questions.

Follow-up questions are included in the case management system for the following assistive products and for rehabilitation service provision: Communication Devices; Wheelchair including pressure relief; Tricycle; Eyeglasses; Hearing Aids; Braces/splints/orthotics; Standing Frame; Walkers/Crutches/Canes; Adapted chair/Cerebral Palsy Chair; Bathing/Toilet devices; Therapeutic footwear; Prosthetics.

d. Empowerment

Data collected from World Vision’s case management system has identified that the highest demand from parents and children is for information and linkage to organizations of persons with disabilities. This demand results from the stigma attached to disability in many communities and to perceptions that a loss of mobility or other functionality makes you less of a person. As a result, empowerment is critical to enabling an individual and their family to access rehabilitation or assistive technology services that they may need. The case management process is designed to provide a CBNS who can encourage and support them and link them to other wheelchair users and the information they need.

In addition, World Vision works to ensure that the community is more accessible. World Vision leverages child protection, education, water, hygiene and sanitation, health, and livelihoods programming in that community to create an inclusive environment including the examples below:
In India, Cambodia, Bangladesh, and Nepal World Vision has worked with Christian, Hindu, Muslim, Sikh, Buddhist, and Bahá’í faith leaders to transform attitudes towards children with disabilities and to use their resources to provide support and services. In Ng’oswet, Kenya, World Vision used the social accountability model, CVA to secure nearly $13,000 from local government to support programs for children with disabilities. In Nepal, World Vision identified children with disabilities in and out of school, made school infrastructure more accessible, trained teachers and administrators in inclusive education and developed braille books, phonic board games and other inclusive learning materials. In Iraq, World Vision made water and sanitation infrastructure in schools, health facilities and camps accessible and empowered organizations of persons with disabilities.

Out of the 7,319 wheelchair users served by WV and partners in the ACCESS wheelchair project, 93% reported increased social inclusion.
Annex 1: Questions related to functional limitations for children under 2

**B1 - 2 to 5 months**
Compared with children of the same age does ____ respond to loud sounds?
- Yes
- No

Watch things as they move?
- Yes
- No

Hold head up when pushing up when on stomach?
- Yes
- No

Bring hands to mouth?
- Yes
- No

**B2 - 6-8 months**
Compared with children of the same age does ____ get things that are within reach?
- Yes
- No

Bring things to mouth?
- Yes
- No

Turn his/her head to sounds?
- Yes
- No

Roll over in either direction?
- Yes
- No
**B3 - 9 to 11 months**
Compared with children of the same age does ____ bear weight on legs with support?

- Yes
- No

respond to own name?

- Yes
- No

babble like ‘mama’; ‘baba’ or ‘dada’?

- Yes
- No

recognize familiar people?

- Yes
- No

**B4 - 12-17 months**
Compared with children of the same age does ____ crawl?

- Yes
- No

point to things?

- Yes
- No

stand when supported?

- Yes
- No

say single words like ‘mama’ or ‘dada’?

- Yes
- No

---

1Taken from the Disability Management Information systems developed in Rwanda
B5 - 18 to 23 months

Compared with children of the same age does ___ notice when a caregiver leaves or returns?

- Yes
- No

know what familiar things are for?

- Yes
- No

speak at least 6 words?

- Yes
- No

walk alone for at least 5 steps?

- Yes
- No

Annex 2: Questions from Child Functioning module for children aged 2-4

| CF7. DOES (name) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING? | Yes.................................1  
No.......................................2 | 2 - CF10 |
|---|---|---|
| CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING? | Some difficulty.................2  
A lot of difficulty...............3  
Cannot do at all...............4 | |
| CF9. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING? | No difficulty......................1  
Some difficulty....................2  
A lot of difficulty..............3  
Cannot do at all...............4 | 1 - CF11  
2 - CF11  
3 - CF11  
4 - CF11 |

CF10. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING?

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

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<tr>
<th>Difficulty Level</th>
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<tr>
<td>No difficulty</td>
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<td>Some difficulty</td>
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<td>A lot of difficulty</td>
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<td>Cannot do at all</td>
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CF11. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND?

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

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<td>A lot of difficulty</td>
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<td>Cannot do at all</td>
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Annex 3: Questions from Child Functioning module for children aged 5-17

**MOBILITY**

CF7. DOES (NAME) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?

Yes................................. 1
No.................................. 2

2 - CF12

CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].

WOULD YOU SAY (name) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

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<td><strong>CF9.</strong> WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].</td>
<td>WOULD YOU SAY (name) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</td>
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<td><strong>CF10.</strong> WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].</td>
<td>WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</td>
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<td><strong>CF11.</strong> WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].</td>
<td>WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</td>
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<td><strong>CF12.</strong> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].</td>
<td>WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</td>
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**CF13.** COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

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**SELF-CARE**

**CF14.** DOES (name) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF?

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

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Annex 4: More details - Mobility and upper body (questions developed with help of experts)

**M1:** Does ____ have weak or floppy leg or arm muscles?

- Yes
- No
- Don’t know

**M2:** Does ____ have tight leg/feet muscles or arm/hand muscles?

- Yes
- No
- Don’t know

**M3:** Does ____ have difficulty moving their legs/feet through the expected amount of movement, or is it difficult for you to move (name)’s legs/feet through the expected amount of movement?

- Yes
- No
- Don’t know
M4) Does ____ have difficulty moving their arms/hand through the expected amount of movement, or is it difficult for you to move (name)’s arms/hands through the expected amount of movement?

- Yes
- No
- Don’t know

M5: Does ____ have movements that are not within their control, such as sudden movements of arms and legs, difficulty moving arms or legs accurately, difficulty controlling head posture?

- Yes
- No
- Don’t know

M6: Does ____ rest with atypical positioning of arms and hands? (Does (name) typically rest with their limbs or whole body in positions that are different from others?)

- Yes
- No
- Don’t know

M7: Does ____ have a sideways curve in their spine?

- Yes
- No
- Don’t know

M8: Does ____’s spine curve forward more than would be typical?

- Yes
- No
- Don’t know

M9: Is ____ able to stand independently and move in and out of standing independently?

- Yes
- No

M10: Does ____ use a standing frame?

- Yes
- No
- Don’t know
M11: Does ___ use a specialized chair to sit in? This could be tilted at an angle, have straps or have other adaptations
- Yes
- No

M12: When using the specialized chair, is ___ able to get in/out independently?
- Yes
- No

M13: Is ___ able to move on the floor independently (roll and crawl)
- Yes
- No

M14: Does ___ use splints or supports?
- Yes
- No

M15: Does ___ use a pen or pencil to draw or print?
- Yes
- No

M16: Does ___ see a rehab professional?
- Yes
- No
Annex 5: Wheelchair specific questions (questions developed with help of experts)

**W1:** What type of wheelchair did ____ receive? (could add a list of wheelchair models with photos specific to the context)

- Stroller/push chair
- Manual for flat or easy terrain
- Manual for difficult terrain
- Sporting
- Powered
- Hand Cart
- Tricycle

**W2:** When was the wheelchair received?

**W2A:** How much did you pay for the chair?

**W3:** What is the life expectancy of the wheelchair according to the wheelchair provider? (could populate automatically depending on the type of wheelchair model identified in W1)

- 1 year
- 2 Years
- 3 years
- Other
- Tricycle

**W3:** Specify Other

**W4:** Was ____ and you provided with training on how to use and maintain the chair?

- Yes
- No

**Did this cover:**

- How to move around in the wheelchair
- Transferring in and out of the wheelchair
- Going on curbs
- Recovering from falls
- Exercises to relieve pressure
- Pumping tires
- Cleaning the frame

**W5:** Was there follow up with ____ 2 weeks after receiving the chair?

- Yes
- No
W6: When was your last contact with the wheelchair provider?

W6A: Was this a visit?

• Yes
• No

W6B: If no, When did you last have a visit with the wheelchair provider?

W7: Is a wheelchair cushion used with this wheelchair? (add images using local examples)

• No cushion used
• Comfort and posture support cushion
• Pressure redistribution cushion
• posture support or pressure redistributing cushions that have been modified for additional support and/or accommodation of hip and pelvis deviation
• Other
• Specify the other type of cushion used

W7A: How comfortable is the wheelchair?

• Very uncomfortable
• Somewhat uncomfortable
• Somewhat comfortable
• Very comfortable

W8: Has ____ had any sores on their body because of sitting in or using the wheelchair?

• Yes
• No

W8A: Where were these?

• On hands
• On bottom
• On back
• On Legs
• On Feet
• Heads

W9: Does ____ use a specialized seating insert or have cushions, straps or harnesses or posture support devices for custom seating in the wheelchair?

• Yes
• No
W10: Since beginning to use the wheelchair, does the user have better arm control, hand control, eye contact, communication, engagement?

- better arm control
- hand control
- eye contact
- communication
- engagement
- no improvement

W11: Since using the wheelchair has the child experienced greater curvature of the spine, shoulder injuries, tight joints, difficulty keeping head upright?

- Curvature of the child's spine
- Shoulder injuries
- Tight joints
- Difficulty keeping head upright

W12: According to the wheelchair provider or therapist, will ____ need to use a wheelchair for the long term?

- Yes
- No

W13: Has ____ been referred to a therapy provider?

- Yes
- No

W14: Is the chair being used every day?

W14A: How many hours a day is (name) using the wheelchair?

W15: How does ____ use the wheelchair?

- Only to sit
- To move inside the house
- To move in the area around the house
- To travel around the community
- To travel outside the community (chair fits in car)
- Others

W15A: If other, please mention

W15B: Can ____ turn the chair themselves?

- Yes
- No
**W15C:** Can ___ propel the chair across the room?
- Yes
- No

**W15D:** Can ___ propel the chair outside the home?
- Yes
- No

**W15E:** Does the chair fit in the house?
- Yes
- No

**W15F:** Does the chair fit into a car?
- Yes
- No

**W15G:** Is there anything that ___ would like to be able to do in their wheelchair but can’t?
- Yes
- No

**W15H:** What is that and why can’t you do that? (if yes)

**W16:** What maintenance work have you done on the chair?
- None
- Pumping tires
- Cleaning the frame
- Replacing the tire
- Fixing a puncture
- Oiling the wheels
- Repairing the frame

- *Take a picture of the child in the wheelchair*
- *Take a short video (less than 20 seconds) of the person moving by themselves in the wheelchair or being pushed in the wheelchair*

**W17:** Is the wheelchair still working as well as when it was provided?
- Yes
- No
W18: What needs to be changed?

- Wheelchair is too small
- Seating support needs changing (foam, cushions, straps or harnesses)
- Wheels are jammed or broken
- The frame is broken
- Tires are worn out
- Brakes not working
- Motor not working
- Steering not working
- Battery not charging or holding a charge
- Battery charging equipment broken
- Castors are wobbly or loose
- Seat is worn or broken

W19: Have you identified how you will repair or replace the wheelchair?

- Yes
- No

W20: What is the challenge around replacing it?

- Don’t Know how to get one
- Don’t have the money
- Can’t Travel
- waiting lists are too long
- No wheelchair services are available locally
- Other
- Outline the other reason

W21: Can ____ transfer to/from their wheelchair independently?

- Yes
- No

W22A: Have you received training on how to safely transfer, handle and lift the user?

- Yes
- No

W22: How many people are required to assist the transfer from the wheelchair?

- Yes
- No

W23: Is transferring ____ difficult for you?

- Yes
- No
W24: Is ___ able to assist with the transfer?

• Yes
• No

W25: Do you use a lifting device to get ___ in and out of the wheelchair?

• Yes
• No

W26: Would you like to know more about how to lift ___?

• Yes
• No

W27: Has ___ or you been supported by a wheelchair user group?

• Yes
• No

W28: Are there any features you like about the wheelchair?

W28A: What features do you dislike, or think could be improved?

W29: Overall what impact has the wheelchair made to x’s life?

• Made it a lot worse
• Somewhat worse
• No change
• Some benefit
• A lot of benefit

Explain:

W30: Overall what impact has the wheelchair made to the family’s life?

• Made it a lot worse
• Somewhat worse
• No change
• Some benefit
• A lot of benefit

Explain:
Annex 6: Referrals triggered by responses to Wheelchair questions:

Depending on responses to questions asked in Annex 5, the following referrals could be triggered in the system:

- Refer to wheelchair provider for more information on lifting and transfers
- Refer to provider for training on how to use and maintain a wheelchair
- Refer to Rehab Professional to address possible damage caused by the wheelchair use including sores, spine curvature, shoulder injury, tight joint and trouble keeping their head upright
- Refer to wheelchair provider to see if the wheelchair is appropriate for needs
- Refer to the wheelchair provider to repair or replace the chair
- Refer for follow up with the wheelchair provider as they haven’t followed up for at least ____ months
- Refer to rehab professional to support transfer to and from the wheelchair
- Refer to a wheelchair user group

Annex 7: Questions related to home environment

Each of these requires a yes/no response and differs according to the age of the child

HE2 Can ___ move about the community independently?
HE3 Can ___ use public or family transport independently?
HE4) Can ___ use public or family transport with assistance?
HE9) Is ___ able to get in and out of your home?
HE10) Is ___ able to get around all parts of the home?
HE11) Is ___ able to get in and out of bed without assistance?
HE12) Is ___ able to make a simple meal independently?
The role of community development organizations in providing holistic wheelchair services

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Please let us know if you have suggestions or comments so that we can enhance future versions of this document.

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3 Idem i
6 Enabling Inclusion – Amar Seva Enabling Inclusion
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