

The benefits of a digital case management for children with disabilities

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Background

World Vision is an NGO operating in nearly 100 countries around the world, mainly in rural areas. World Vision seeks to serve the most vulnerable children, including children with disabilities, and their families through multi-sectoral programming including health, education, water and sanitation, child protection and livelihoods. World Vision set an ambitious target at the 2022 Global Disability Summit; to increase the number of children with disabilities it serves by five times by the end of 2026. To do this, we needed to overcome three key barriers that have limited our ability to serve more children with disabilities:

1. **More effective identification of children with disabilities** – programs and projects have not been using the Child Functioning module questions to identify children with disabilities
2. **Knowing how to support children with disabilities** – World Vision wasn't clear on its role in supporting communities to meet the needs of children with disabilities living in rural areas. Sector-specific programs were not adapted to serving the needs of children

with disabilities and their families, for example by ensuring the construction of accessible water points and latrines in schools and homes.

3. Ensuring cost-effective referral systems – by:

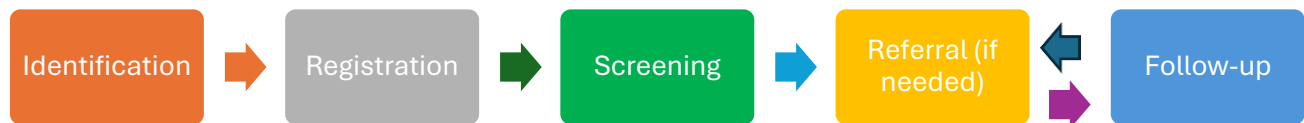
- a. linking children with disabilities in rural areas with specialized disability services in urban areas in a way that reduces cost without compromising on quality and
- b. supporting follow-up to ensure that those services are having the desired impact on the child.

With most service providers located in urban areas, people in rural areas have faced multiple barriers in accessing services including a lack of information about services, cost to travel, loss of income when traveling and service cost. Urban providers can't normally travel to rural areas because they don't know who needs the service and often don't have a budget, transportation or infrastructure that supports services in rural areas. With the poverty of most families of children with disabilities and budgetary limitations for service providers, it is essential to maximize the efficiency of service provision. Under the new Bill for persons with disabilities in Malawi, there is a requirement for the health system to provide effective referral from primary to tertiary providers. World Vision has collaborated with urban service providers in very limited locations by supporting mobile clinics and the use of telemedicine, but a more comprehensive, sustainable system needs to be developed that is evidence-based.

To overcome these major barriers, we designed a case management system for children with disabilities. At a very minimum, we understood that we could address the first and second barriers and start to generate data that would inform a strategy to address the third barrier. The case management system has been tested in Malawi in five rural districts in a mix of communities where we have an existing presence and some where we don't. This is the foundation of the 'Able to Thrive' program. In both situations, we are working in partnership with the Malawi council for disability affairs (MACODA). MACODA has a network of paid community-based rehabilitation staff and outreach volunteers. The case management system has been developed to support a process of identification, registration, referral and follow up.



Originally, screening was not part of the process, and this has now been added by Malawi as an additional step prior to referral to ensure the accuracy of actions recommended by data generated at registration:



Prior to running the case management system, World Vision created an enabling environment over two years to support this system in Malawi. Staff were trained using the ‘Traveling together’ methodology, an 8 hour in-person training. This challenged existing norms and stereotypes regarding disability and helped them to understand how they could better meet the needs of children with disabilities in their programming. World Vision also built referral partnerships with government, private sector and NGO specialized service providers in key sectors including provision of assistive devices, rehabilitation, the association of the deaf (MANAD) and vision and hearing service providers.

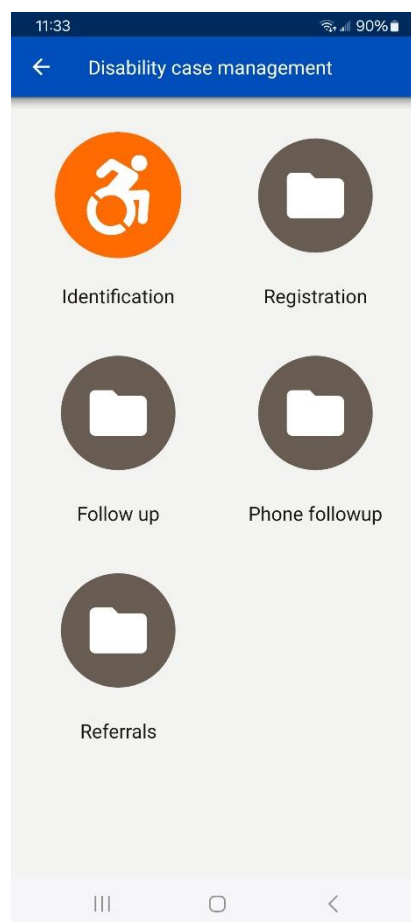
The case management system

The case management system is run on Android mobile phones and works on and off-line. The application was developed on the CommCare system in English and has been translated into Chichewa as well as Spanish and French ready for adoption in other countries. The system has been used by 230 people in Malawi, largely by World Vision volunteers who are used to collecting data on children within World Vision’s sponsorship program. Most have a secondary school level of education or higher but no background or training around disability. Some of the volunteers received training around early identification of children with disabilities. Volunteers have worked with MACODA staff who are responsible for supporting the needs of persons with disabilities.

As of August 2nd, 2024, 4,174 had been assessed using the identification module and 3,574 children had been registered as having a disability. World Vision worked with MACODA to identify children who likely had a disability based on existing information. The identification module could also be used for all children within a household survey. We have learnt that there are more children than were originally identified that have a disability in the community. Some children are only identified when they arrive for a mobile screening clinic or parent support groups organized by World Vision. This may be because parents realized that World Vision was ready to support their children and were therefore less concerned about issues of possible stigma around having a child with disability. It may also be that they only felt that only specialized assistance (rather than a community volunteer asking questions) would help. The follow-up module has been used for only 35 children and will be expanded over the next few months. The average amount of time spent on the identification module has been about 15 minutes and a further 20 minutes for registration with some lasting an hour and a half. If data collection was the purpose, this might be too long, but the focus is on case management and building a relationship with the parent and child, so this

time is appropriate. The questions on registration were different for each child as they were specific to the type of disability identified and responses to subsequent questions.

The identification module uses different tools to identify children who likely have a disability. For children under 2, there are four questions related to functions that they should be able to perform at that age. If they are unable to, they are then referred to a medical professional to assess if they have a disability. The Malawi Development Assessment tool (MDAT) was also added but not used for formal identification purposes. As the MDAT is longer and is meant to be observed, it is not as suitable for asking to parents. For children aged 2-17, the appropriate Washington Group child functioning module for that age is used. If the response was a ‘a lot of difficulty’ or ‘cannot do at all’, they were considered to have a disability. Additionally, if they already used an assistive device to enhance functionality, they were considered as having a disability, allowing follow-up to ensure that the device continues to be functional and improving child function. Additional questions were added to identify if a more accurate assessment of children who needed support could be identified. A question related to albinism was added based on feedback in Malawi.



The registration module is designed to provide a set of questions that will allow the case worker to get a complete understanding of the child and their family. Based on their responses, a set of recommended actions is generated from a total menu of 135 actions. Currently, this list has been shared with the parents at the end of the session, however not all the recommended actions might be necessary. The other challenge is that children with multiple disabilities may have many recommended actions and prioritization is needed. Therefore, we are discussing if these recommended actions would be kept for internal use to develop a more concrete plan in consultation with qualified individuals.

The registration module collects data on parental and child attitudes to disability (as a key determinant of likely long term outcomes and measure of well-being), their home environment, their functionality and general health. There are no questions directly related to poverty status as the program was concerned about what it might be able to do in response but there are proxy indicators around the ability to afford uniform for school. Registration uses the draft Washington Group inclusive education modules to identify their educational status and information on their school environment if attending. These

questions will be repeated during follow-up each six months to allow a comparison from a baseline of registration. The process also asks questions related to assistive devices that they already have. Based on feedback in Malawi, we added specific questions and recommended actions around albinism and visual impairment.

The follow-up module identifies if the recommended actions identified at registration have been completed. If they haven't been completed it asks why they haven't been completed. The module also repeats questions asked at registration as outlined above. If an assistive device has been received since registration, relevant questions will be asked. The idea behind follow-up is to ensure that the devices are used and these as well as rehabilitation and medical interventions are improving function. There are two follow-up forms, one for a home visit that is more detailed and one for a phone follow-up that checks in to see if an action has been taken. In Malawi, the phone number may be that of a neighbour or relative if they don't have their own phone.

In addition to these four key modules – identification, registration, follow-up and phone follow-up, there is a **referral section**. This section can be used to provide service providers with data from the four key modules and for them to enter their own information when they are providing services. In locations where providers don't have their own information management system, the application can provide this for them. Note that the system doesn't automatically refer a child with disability to a service, that is still the responsibility of the case manager with the program officer through a phone call or email. Based on feedback in Malawi, we created a screening module as part of this referrals section. Malawi has created a mobile screening intervention where different specialists come together in a community location to assess the children who have been identified as having a disability in that community. The results from that screening can now be entered into the application. As of August 2nd, 2,647 results have been entered into the system. Some children have more than one screening record as they were seen by more than one specialist. The screening process includes actions recommended by the specialist. In Malawi, the results from the screening have driven additional specialist referrals as necessary.

The benefits

So far, program staff are coming to understand the potential of the application to support improvements in programming. Staff can generate reports from the data, but we have not yet developed PowerBI dashboards that would enable that data to be more accessible. This is planned for the next 3 months. Initial benefits of the system have been:

1. *Improved understanding of issues facing children with disabilities and their families* – using the questions generated by the application has provided a much more comprehensive understanding of the holistic issues

2. *Keeping track of numbers* – using the reporting feature we can identify number of children who have completed information on each module and then disaggregated that geographically, by user.
3. *Analyzing data for programming* – we have already used data around education to produce a report providing invaluable insights into challenges around education for children with different types of disabilities. This data has informed the development of our Learning Passport activity with parents and children. The content for the activity was defined based on the data around the barriers identified by parents and children to accessing quality education. The program team has also worked with child protection, livelihood, water and sanitation and health sectors to identify ways that existing sector programs can meet the needs of children with disabilities and their families identified by the data. We will continue to use data insights to monitor the effectiveness of existing interventions and make changes as necessary.
4. *Advocacy* – World Vision was able to present the data related to education in Malawi at the Global Disability Summit with representatives from the Ministry of Gender (who are responsible for disability issues), the Ministry of Education and MACODA. The use of analyzed data in future will be critical in helping the government to fulfill their commitments under the 2023 Persons with Disabilities Bill.
5. *Identifying specialists needed for mobile screening and which children need to attend* – The registration data indicates the kinds of services that the children are likely to need. This allows us to invite the right specialists and right children to community screening events. If children can't come to events, then home visits can be arranged.
6. *Quality assurance* – The program managers and I can review the data collected for accuracy, monitor trends and identify issues that need to be addressed within the system or with the case managers.

Potential benefits

Outlined below are potential benefits based on enhancements to the application and the way that the application is being used.

1. *Utilizing the follow-up module to its fullest extent* – Currently the follow-up module hasn't been used at scale. This is primarily because the focus has been on identification and registration during the project's start up process. As we use the follow-up module more, we will be able to understand its potential for improving the process. It will be critical to assess the use of assistive devices as previously there has been significant levels of abandonment or underuse, times when the devices haven't worked, and no action has been taken to repair them or device users have not had the training they need to use the devices effectively.
2. *Integrating data from the screening process into recommended actions* – The actions from the screening process are currently not integrated into the follow-up module. This will need to happen prior to the use of the follow-up module at scale.

3. *Prioritizing and managing recommended actions* – Discussions will need to happen within the program to determine the best way to do this. Options are to see if the recommended actions can be limited or prioritized automatically or if a specialist needs to do this.
4. *Enhancing the understanding of case management* – As many of the persons who have been using the application are used to collecting data, they have not taken on a role as a case manager. They have not fully understood that the questions in the application are a guide to support a process of building trust with the child and their family and understanding their needs. They have also not always empowered and encouraged the children to respond to questions. In addition, MACODA should be managing these cases in the long term and more work will be needed to increase their ownership over the process. This will likely require the procurement of devices to support MACODA.
5. *Analyzing data for improved system performance* – As outlined above, one of the challenges has been around the cost-effective provision of services in rural areas. Much more can be done to address this. For example:
 - a. Initially there were no plans to screen all children using mobile clinics. The idea was to use data collected during identification and registration to limit the numbers of children that received specialized assistance. We can now compare data collected during identification and registration to results from the screening to see if we can accurately predict which children are most likely to need specialized assistance. We can then decide if mobile screening needs to be a core intervention, and which type of children need to participate.
 - b. The Malawi Development Assessment Tool questions were also integrated into identification for children 3 and under but they haven't been used to identify if a child has a disability. We can compare data from the MDAT with data from the child functioning module for children aged two and above and the four age-related questions for under 2s to identify differences in results.
 - c. As service providers use different provision modalities – in-person vs telemedicine, direct vs parent-led etc., we can understand the relative change in functionality and therefore cost-effectiveness.
 - d. If we digitize the referral process, we may be able to learn more about how to enhance referrals

Benefits for other countries

The current application was developed initially without a particular country in mind. It was designed to be self-contained in being used by community-based case managers identified by World Vision or others. These could be community volunteers, health, education, child protection or community-based rehabilitation workers in different contexts. Case managers would use registration data to identify actions, those actions would be turned into referrals or community-based actions and then the follow-up module would find out if the recommended actions had been completed and if improved functionality and well-being

had been achieved for the child. Based on feedback from Malawi, the system was adapted so organizations providing specialized services could also use the system. This adaptation has not yet been optimized.

Other countries seeking to replicate the case management system will need to identify if the conditions to use the system will be consistent with their context and what adaptations might be needed. Some key questions include:

- Who are the case managers? What level of education or support will they need? Will they do a household level identification or focus on children who likely have a disability? Do they have devices, or will these need to be provided?
- Are the referral systems in place for all the different services required by the recommended actions? If not, should the questions related to those services be removed or efforts made to develop or secure those services?
- How is referral initiated? Through phone, email, other method?
- Will mobile screening services be provided?
- Is there an existing case management that service providers use to manage clients and services? If not, do the service providers want/have the capacity to use the application for their own data?

Other potential adaptations necessary will be contextualization of specific questions around government services, translation and the removal of questions and recommended actions related to services that are unavailable. We will roll the case management system out to Honduras and Mozambique in the short term so that we can continue to learn and test the system in different contexts.

Benefits for supporting other vulnerable groups

The case management system could be adapted to include adults and other vulnerable groups. Additional questions can be added to address vulnerability related to child labor, trafficking, gender-based violence or other factors of interest.